

Research Project Portfolio
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**Accepting the 'Big C': Exploring the acceptance – quality of Life
relationship in a cancer population**

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“Is it not for us to confess that in our civilized attitude towards death we are once more living psychologically beyond our means, and must reform and give truth its due? Would it not be better to give death the place in actuality and in our thoughts which properly belongs to it, and to yield a little more prominence to that unconscious attitude towards death which we have hitherto so carefully suppressed? This hardly seems indeed a greater achievement, but rather a backward step...but it has the merit of taking somewhat more into account the true state of affairs.”

-Freud, 1915

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Thanks too to my wonderful family, my partner Harry, and my friends for their constant love and support, and for being so understanding of the seemingly endless deadlines the last three years have required of me. You have kept me smiling all the way through. In writing this project, I would also like to remember Edward Watson - a true intellectual and a dear friend, whose passion, talent, and aptitude for science inspired all those who knew him, and whose attitude towards cancer was truly remarkable until the very end.

Portfolio abstract

There is a high prevalence of distress amongst cancer patients, with up to 40% reporting clinically-significant levels of distress, such as depression, anxiety, and death anxiety. Acceptance and Commitment Therapy (ACT) has a growing evidence base in health populations, such as in diabetes and chronic pain, counteracting the avoidant behaviours which are negatively implicated in outcomes. ACT claims that experiential acceptance is key to shifting the avoidant responses people exhibit towards their inner experiences and psychological pain. Thus far, there is limited research exploring ACT processes within a cancer population. Traditional existentially-informed theory has claimed that accepting death anxiety would be psychologically paralysing and that mortality must be defended against, yet evidence for acceptance suggests the opposite. This study therefore aimed to explore the relationship between acceptance and outcomes of quality of life and distress in a cancer population, in order to explore the implications for an accepting response style, and also whether avoidant or approach response styles were implicated in better or worse psychological outcomes.

Using a longitudinal design, six standardised questionnaires, well-utilised in cancer populations, were issued to 72 adults with experience of cancer, measuring clinical variables, cancer appraisals, response styles, and both quality of life and distress outcomes. The addition of a follow-up questionnaire, completed by 31 participants after three months, allowed for predictive and cross-lag analyses to be carried out. Results showed acceptance to be an independent explanatory and predictive response style variable for both quality of life and distress outcomes, in the direction of psychological health. 'Avoidant' response styles were negatively implicated in outcomes, and many 'approach' response styles other than acceptance did not reach correlational significance with outcome variables. Acceptance and avoidant response styles remained stable over time, whilst outcomes continued to change, and acceptance was thought to be driving future outcomes in a one-way direction.

The findings support the notion that experiential acceptance is implicated in beneficial psychological outcomes for cancer populations, rather than being detrimental to functioning, as suggested by existential theorists. Acceptance demonstrated significantly more influence over outcomes than either disease characteristics or threatening illness appraisals, and may influence future functioning. Furthermore, avoidant responses to cancer-related experiences were negatively implicated in psychological distress and also quality of life, which continued to deteriorate over time despite avoidant response styles remaining stable. Acceptance may be a helpful and influential response style, given that it predicts and potentially influences future functioning, and may provide a reasonable treatment target for psychological intervention with cancer patients, over and above the direct targeting of cancer appraisals.

Statement of contribution

This research project is the result of my own original work, which began upon my enrolment on the Trent Doctorate in Clinical Psychology (DClinPsy) course, in late 2013. The project idea was borne during a research meeting with my chosen research supervisors, Drs Nima Moghaddam and David Dawson, and followed my interest and previous experience in working with a cancer population. My supervisors provided regular support and supervision throughout the project, either face-to-face or via email communication. They have also given feedback on sections of my journal article. As the chief investigator for this project, I have been responsible for: obtaining ethical approval from the University of Lincoln, NHS ethics boards, and permissions from NHS Trust Research and Development teams; forming relationships and attending meeting with clinical gatekeepers; online advertising and recruitment of participants; data collection and storage (including devising a system whereby paper responses could be identified by administrative staff and stored securely at the University of Lincoln); data entry; data analysis (with additional support from Dr Nima Moghaddam); and the write-up of the project, which forms this thesis.

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JOURNAL ARTICLE

Accepting the ‘Big C:’ Exploring the acceptance – quality of life relationship in a cancer population

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Abstract

Objective. 40% of cancer patients may experience clinically-significant levels of distress, yet evidence for appropriate psycho-oncological interventions remains lacking. This study aimed to explore acceptance, as defined by acceptance and commitment therapy (ACT), in cancer patients. Primary aims investigated whether acceptance was related to and predictive of better quality of life and distress outcomes, and whether acceptance interacted with cancer appraisals to influence outcomes.

Design. Longitudinal, quantitative design with a follow-up after three months. Participants completed a battery of questionnaires at times one and two.

Measures. 72 participants completed standardised questionnaire batteries comprising: Brief Illness Perception Questionnaire; Brief COPE; Acceptance and Action Questionnaire II; Hospital Anxiety and Depression Scale; Functional Assessment of Cancer Therapy – General (FACT-G); and Death Anxiety Scale (DAS). 31 participants repeated the battery after three months.

Results. Acceptance was an independent explanatory and predictive variable for quality of life and distress scores, in the direction of psychological health, and predicted functioning over time. Acceptance had greater explanatory power for outcomes than either cancer appraisals or avoidant response styles, including denial and self-distraction. Avoidant response styles showed significant associations with outcomes, but in the directions of greater distress and poorer quality of life.

Conclusions. The findings support the role of an accepting response style in improved psychological outcomes. Avoidant responses were consistently related to poorer outcomes in a population with distress and death anxiety. Acceptance predicts functioning, and is supported as a helpful response style for cancer patients.

Key words: *ACT, Acceptance, Death, Cancer, Quality of Life, Distress*

Introduction

Cancer and experiential distress

In the UK, an estimated fifty percent of people born post-1960 will experience cancer in their lifetimes (Cancer Research UK, 2014). During the phases of diagnosis, treatment, and remission, as many as 75% of cancer patients experience psychological distress (Cardy et al., 2006), reduced quality of life (QoL) (Ciarrochi, Fisher, & Lane, 2011), and heightened levels of anxiety, grief, pain, fatigue, death anxiety, and depression (Barracough, 1999). Such difficulties are thought to become clinically significant in 30%-40% of patients (Cardy et al., 2006; Ciarrochi et al., 2011; Mitchell et al., 2011), yet there remains a wide gap between recommended levels of psycho-oncological care, and the 10% of patients who actually receive it (National Institute for Clinical Excellence, 2004; Ramachandra, Booth, Pieters, Vrotsou, & Huppert, 2009). Distress in cancer patients may be a response to real or threatened loss across many domains, such as physical wellbeing, body image, self-esteem, independence, work, role, relationships, sexual function, and life expectancy.

Although survival rates are continually improving, cancer remains a very real threat to life, killing 162,000 people in the UK annually (Cancer Research UK, 2014). Many cancer patients consequently report intrusive thoughts and worry in relation to their survival, and preoccupation with existential thoughts and death anxiety (Adelbratt & Strang, 2000). Patients may also experience trauma and grief reactions when confronted with their existential vulnerability, with those who try to avoid cancer-related cognitions and behaviours at greater risk of distress (Angiola & Bowen, 2013). Death anxiety is described as “an emotional reaction involving subjective feelings of unpleasantness and concern”, evoked by “the anticipation of a state in which the self does not exist” (Hoelter, 1979; Tomer & Eliason, 1996), and correlates with general anxiety, depression, and perceived shortened life expectancy¹. Death anxiety may also occur alongside sadness, hope, and despair (Ciarrochi et al., 2011).

Although distress occurs across the disease trajectory, advanced cancer patients may experience different appraisal and response styles (Rinaldis, Pakenham, Lynch, & Aitken, 2009), higher rates of distress (Vodermaier, Linden, MacKenzie, Greig, & Marshall, 2011), and high death anxiety (Adelbratt & Strang, 2000; Neel, Lo, Rydall, Hales, & Rodin, 2015). Patients with aggressive or late-stage pancreatic, lung, and prostate cancers report greater levels of distress and suicidal risk (Bill-Axelsson et al., 2010; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), as the subjective and objective threat to life increases. It is logical to suggest that levels of distress and anxiety may therefore augment in line with worsening prognosis and perceived severity of the disease (Gao, Bennett, Stark, Murray, & Higginson, 2010; Rinaldis et al., 2009), and that increasingly-proximal threats to life may affect appraisal, response styles, and distress. It is also clear that not everyone with cancer experiences acute emotional suffering, even at the end of life, and that there are probable mechanisms, beyond objective disease status, which influence acute distress and warrant further investigation.

¹ For a discussion of distress measurement in cancer populations, see Extended Paper (EP) 1.1 – 1.1.2

Terror Management Theory, ACT, and response styles in cancer

Some research has suggested that death anxiety results from unresolved psychological distress and maladjustment, rather than from simply having cancer (Gonen et al., 2012). Conversely, Terror Management Theory (TMT) (Greenberg, Pyszczynski, & Solomon, 1986) suggests that death anxiety is innate and universal, with the degree of death awareness varying between individuals; potentially being higher in those whose lives are more threatened by disease². TMT suggests we must stave off the ‘terror of death’ through the defensive mechanisms of thought suppression, cultural belonging, and self-esteem (Greenberg et al., 1986); the latter providing significance, meaning, and a sense of permanence (Mosher & Danoff-Burg, 2007). The idea of meaning-making is also incorporated within models of grief (Hall, 2011; Jim & Andersen, 2007; Tolstikova, Fleming, & Chartier, 2005); implying that a breakdown in the defensive strategies of meaning-making and self-esteem bring the terror of death into awareness. TMT suggests that defences must therefore be strengthened, to alleviate this distress, and to facilitate psychological survival and functioning (Mosher & Danoff-Burg, 2007), yet the negative effects of such avoidant response styles upon psychological outcomes may be severe.

Defence mechanisms are akin to avoidant response styles³, used in the attempt to ward off the internal experiences associated with cancer. According to TMT this avoidance is key to psychological survival, but emerging evidence for the role of acceptance in physical health populations supports an alternative model of psychological functioning and intervention. Acceptance and Commitment Therapy (pronounced “ACT”) (Hayes, Strosahl, & Wilson, 2011) suggests that avoidance of inner experiences, such as death anxiety, comes at a high cost to the individual, and does not provide a successful or protective long-term solution. Attempts to suppress thoughts have been shown to heighten their frequency and emotional salience (Hayes et al., 2011), and as a corollary, problematic avoidance behaviours increase (Solomon, Greenberg, & Pyszczynski, 2015), through attempts to escape an increasing number of anxiety-eliciting related stimuli⁴.

Accordingly, avoidant responses, including denial, disengagement, self-blame, and emotion-focused control, are associated with anxiety, depression, lower treatment compliance, and poorer quality of life in cancer patients (Carver et al., 1993; Hulbert-Williams, Storey, & Wilson, 2015; Nipp et al., 2016; Šoštarič & Šprah, 2004; Stanton, Kirk, Cameron, & Danoff-Burg, 2000). Approach-oriented responses, which facilitate the expression of affect, are instead linked to better adjustment and quality of life in cancer (Stanton et al., 2000). Furthermore, research has implicated the role of illness appraisals in determining distress, yet attempts to directly modify these appraisals, as might be applied in Cognitive Behaviour Therapy, encounter the same limitations as thought-suppression (Villardaga, Hayes, Atkins, Bresee, & Kambiz, 2013). Attempting to modify appraisals may also be inappropriate, for example, when thoughts about the end of life may be accurate, rather than dysfunctional. This scenario warrants an alternative route for intervention, providing scope to investigate whether cancer- and death-related thoughts and feelings can be safely accepted and experienced, rather than avoided.

² For death anxiety, ACT and TMT, see EP 1.2 – 1.2.2

³ For coping and response styles, see EP 1.3 – 1.3.4

⁴ For an overview of the role of verbal language in experiential avoidance, see EP 1.4

Accepting distress in cancer

ACT⁵ belongs to the ‘third-wave’ family of cognitive and behavioural psychotherapies, and seeks to change relationships to psychological events, rather than to directly lessen, control, or substitute the events themselves⁶ (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Hayes et al., 2011). In contrast to TMT, ACT would therefore suggest that attempts to avoid and control painful cancer-related inner experiences inadvertently create a state of suffering and unhelpful ‘experiential avoidance’. Thus, we cannot and should not attempt to avoid psychological pain, which is a normal and ubiquitous part of life, as the ensuing struggle with avoidance narrows our engagement with valued behaviours and creates suffering (Hayes & Smith, 2005).

One of the six, interconnected core processes⁷ in the ACT model of psychological flexibility is acceptance⁸. In ACT, acceptance is not a state of tolerance or resignation, but a willingness to allow all thoughts and feelings to occur without judgement or avoidance; an attitude and process detrimental to taking healthy, valued action. Acceptance is therefore the opposite to the experiential avoidance thought to underpin poor psychological health, anxiety, and depression⁹ (Kashdan & Rottenberg, 2010), and also diametrically opposed to the response styles advocated by TMT. Through acceptance and mindfulness processes, people become free to engage in more valued activities (Ciarrochi et al., 2011), and experience lower levels of depression, increased coping, and reduced pain behaviour (Jacob, Kerns, Rosenberg, & Haythornthwaite, 1993). Understanding acceptance may be particularly relevant to health populations, where an unwillingness to experience painful thoughts and feelings has been shown to predict psychological distress, depression, disability, and persistent pain (McCracken, 1998).

This research explores whether acceptance may be an alternative and beneficial approach to the avoidance of death and cancer-related experiences. High levels of death anxiety in cancer patients suggest that any ‘defences’ have become ineffective, and may serve the function of experiential avoidance. When death-related thoughts and feelings augment in response to the threat of cancer, defences and experiential avoidance may escalate, proliferating suffering (Hayes et al., 2011). Thus, suffering is the result of an avoidant response to internal experiences, rather than a direct corollary of those internal experiences themselves. Furthermore, TMT suggests that valued behaviours should be increased as a defensive strategy against death-related feelings, though this may only serve to increase experiential avoidance (Ciarrochi et al., 2011). How then, to enable valued living, as both ACT and TMT suggest, if this only serves to increase avoidance and the salience of distressing internal experiences? Acceptance is one potential solution, and when adopted, means that engaging in activities no longer functions as an avoidance strategy. Instead, valued activities are undertaken alongside the psychological pain that is evoked by cancer’s threat to life expectancy and the experience of personal loss. Given the deleterious impact of experiential avoidance, the acceptance of death anxiety and cancer-related inner experiences may relate positively to psychological

⁵For an overview of ACT’s background, see EP 1.5

⁶For an overview of ACT’s epistemological position, see EP 4.1 – 4.2.1

⁷For five of the core processes of ACT, see EP 1.6 – 1.6.5

⁸For acceptance, see EP 1.7 – 1.7.3

⁹For an ACT conceptualisation of psychopathology and wellbeing, see EP 1.8

flexibility, distress, and quality of life. Furthermore, as death anxiety is not acute in all cancer patients, this may indicate that certain response styles are implicated in better or worse psychological outcomes.

Present study

In physical health populations, ACT is effective for chronic pain, addictions, psychosis, diabetes, HIV, and epilepsy (e.g. Davis, Morina, Powers, Smits, & Emmelkamp, 2014); reducing distress and improving quality of life. Although studies into ACT and cancer remain few, initial research is promising and nascent (Hulbert-Williams et al., 2015; Low et al., 2016), with evidence for mindfulness interventions in cancer slightly better established (Piet, Würtzen, & Zachariae, 2012). Existing ACT studies have often recruited for specific types or stages of cancer, with female breast cancer patients being over-represented, and those with advanced cancer or in remission being under-represented (Rand et al., 2012; Stanton, 2012). Studies are frequently of cross-sectional design, potentially limiting the generalisability of results and opportunities to consider changes in response processes over time. A need for longitudinal and processual studies on ACT in cancer has been identified (Dunne et al., 2016; Rand et al., 2012), with this paper marking only the fourth non-interventional study of ACT in cancer, in order to better understand the processes underpinning ACT interventions in this population. There have also been calls for research into appropriate psychotherapeutic approaches in palliative populations (Zimmermann, 2012); a sample included within this study¹⁰.

As ACT is effective for treating problems relevant to cancer patients, such as anxiety and depression, it seems plausible to investigate ACT processes within this population, particularly given the death-avoidant strategies recommended by TMT. Acceptance-based interventions may provide a plausible alternative to these avoidant response styles in cancer patients (Hulbert-Williams et al., 2015), and this study aimed to investigate this premise by examining the relationships between acceptance, distress, and quality of life in a broad sample of cancer patients.

Methods

Aims and design

The primary aims of this study were 1) to discover whether acceptance was related to quality of life and distress outcomes in cancer patients, and 2) whether acceptance moderated any relationship between cancer appraisal, and quality of life, and distress outcomes (Figure 1). Secondary aims were to examine 3) whether sample characteristics and alternative response styles were also related to quality of life and distress outcomes, and 4) any temporal relationships between acceptance and outcomes, across time points one and two.

¹⁰ For a review of the evidence for psycho-oncological interventions, see EP 1.9 -1.9.1

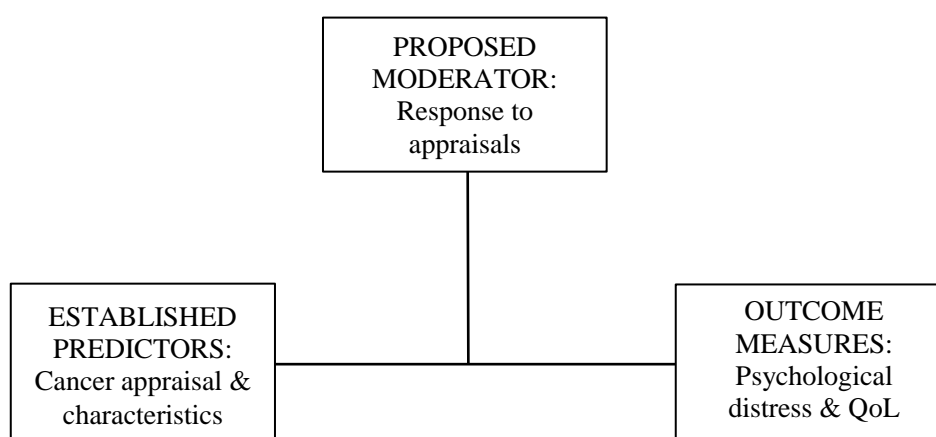


Figure 1: *A priori* conceptual model of the variables examined in the study

The study used a longitudinal, quantitative design. Participants completed several demographic and clinical questions, and a battery of six standardised questionnaires¹¹, which measured cancer appraisal, response styles, and both psychological distress and quality of life. The study was granted ethical approval by the University of Lincoln and an NHS Ethics Committee¹², with R&D approved locally by four participating NHS trusts.

Participants and procedure

A priori power calculations estimated that at least 32 participants were needed to detect an acceptance-quality of life correlation with a medium effect size (based on a correlation derived from previous research (Hulbert-Williams et al., 2015)). The calculation was based on an alpha of 0.05 ($p < 0.05$), a power of 0.80, and was also of sufficient power to detect medium effect sizes or larger with the inclusion of 16 potential predictor variables in the regression analyses ($\alpha = .05$, $\beta = .80$). Over-recruiting was deemed desirable, to allow for attrition and to power any later multivariate analyses (which were contingent on the correlational outcomes). 74 participants were recruited at time one, but two data sets were excluded due to having missing data on over 20% of the questionnaire; a threshold utilised elsewhere in research (e.g. Gillanders, Sinclair, MacLean, & Jardine, 2015). Pairwise deletion was used appropriately for the remaining items with missing data (Tabachnick & Fidell, 2007), as the relatively few missing data (7.4%) was shown to be concentrated across a few variables and missing completely at random (MCAR), as established by Little's test ($\chi^2 = 321.54$, $df = 283$, $p = .057$).

Participants with current or historic cancer were invited to the study via one of two recruitment streams. They were either identified and approached by NHS clinical gatekeepers, or self-selected via advertisements placed online. Clinical gatekeepers were recruited from hospitals, hospices, and community services in Nottinghamshire, from where they identified potential participants and distributed questionnaire packs. Packs contained participant information sheets, consent forms, questionnaire batteries, and return envelopes. Online participants were targeted through adverts placed on social media platforms and cancer support websites, such as Facebook, Twitter, and Cancer

¹¹ For more detail about the study methods, see EP 2.1 – 2.1.5

¹² NRES East Midlands; application reference 14/EM/1224

Chat. Online participants were provided with the same information as paper participants, which they accessed via a link to an online survey programme. Consenting participants were eligible if they were over 18 years old, had experience of cancer, and lived in the UK. All participants were invited to take part in a follow-up questionnaire, which took place three months after initial participation. The overall sample size was $n=72$ for time one, and $n=31$ for the follow-up. The online and paper samples were similarly sized: 48% of total participants completed paper questionnaires, and 52% completed online questionnaires. Whilst the online sample contained significantly more younger, female participants than the paper sample, there were no significant differences between samples in terms of cancer stage or number of previous cancers.

Measures

A questionnaire battery was administered to measure three domains: predictor variables (demographics, cancer characteristics, and appraisals); response style variables (responses to appraisals); and outcome variables (quality of life and distress) (see Table 1).

	1	2	3
Theoretical category	<i>Established predictor variables</i>	<i>Response style variables</i>	<i>Outcome variables</i>
Conceptual targets	Appraisal-focused measures; The experience of having cancer	Response-focused measures; Response styles to cancer-related appraisals	Psychological outcome measures
Measurement targets	Demographic and clinical variables; cancer characteristics & beliefs	Acceptance and alternative response styles	Quality of life and distress
Measures used	Brief IPQ Age Education Religion/spirituality Psychological support Bereavement Cancer site Cancer stage No. previous cancers	AAQ II Brief COPE	FACT-G HADS DAS

Table 1: Theoretically-informed measurement framework and the measures used in each category.

The following standardised measures of appraisal, response styles, and outcomes were issued¹³:

Appraisal measure: Brief Illness Perception Questionnaire (Brief IPQ)

The Brief IPQ (Broadbent, Petrie, Main, & Weinman, 2006) is a nine-item questionnaire assessing the cognitive and emotional representations of illness. It is quick to administer and therefore suitable for populations who may feel unwell (Ng, 2012), and has good test-retest and discriminant reliability, and predictive and discriminant validity (Van Oort, Schröder, & French, 2011). Cronbach's alpha was low ($\alpha=.38$), but the scale was adapted to the population as recommended (Broadbent et al., 2015), and remains common in studies of health populations.

Scale items were made specific to a cancer population, e.g. by substituting the wording of 'illness' for 'cancer,' and to improve the comprehensibility of items 3, 7, 8, and 9 as recommended (Broadbent et al., 2015). The anchoring system was also adapted to that of the IPQ-Revised, as research had previously identified that the existing 0-11 ratings scale was unsuitable for those with short-term prognoses when answering the timeline item (Price et al., 2012). The five-item Likert scale from the IPQ-Revised was therefore adopted, with response anchors of 'strongly disagree' and 'strongly agree.' The IPQ-Revised also has good psychometric properties for the cancer population (Ashley et al., 2013). Higher Brief IPQ scores reflect a more threatening view of the illness.

Response style measures:

Acceptance and Action Questionnaire II (AAQ II)

The AAQ II (Bond et al., 2011) is a seven-item measure of psychological flexibility and acceptance, and in this study was scored in the direction of higher scores indicating greater experiential acceptance (rather than experiential avoidance). Use of the AAQ II is well-established in the ACT literature, and has been deemed to be of satisfactory reliability and validity in general research and with cancer populations (Bond et al., 2011; Feros, Lane, Ciarrochi, & Blackledge, 2013). Cronbach's α was established at .85.

Brief COPE

The Brief COPE (Carver, 1997) measures coping (response) styles across 28 items on a Likert scale. Although the author does not specify aggregates for the fourteen response styles assessed, later research has suggested problem-focused coping, and active emotion/avoidant emotion coping (Gillanders et al., 2015). The Brief COPE has been used in cancer populations of varying cancer sites and stages, and has adequate validity and reliability for cancer populations (Yusoff, Low, & Yip, 2010), with Cronbach's α reaching .82 in this study. Higher scores reflect greater use of particular response styles.

Outcome measures:

Functional Assessment of Cancer Therapy - General (Fact-G)

¹³ For a more extensive discussion of the measures chosen, see EP 2.2

The FACT-G (Cella et al., 1993) is a widely-used measure of cancer-related quality of life (Ciarrochi et al., 2011) across four domains on a Likert scale: emotional, functional, physical, and social. It has total score reliability within the range of .80-.96, and good validity; established across cancer subtypes (Webster, Cella, & Yost, 2003), and through correlations with other health-related quality of life measures, mood, and anxiety (Luckett et al., 2011). Cronbach's α ranged between .77 and .86 for each subscale. Higher scores suggest better cancer-related quality of life.

Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) is a 14-item measure of anxiety and depression, widely used and validated in a range of patient populations, including different cancer subtypes, and palliative and non-palliative populations (Mitchell, Meader, & Symonds, 2010; Vodermaier, Linden, & Siu, 2009). The HADS has high validity and reliability for cancer populations (Mitchell et al., 2010), and is an effective screening tool for anxiety and depression (Mitchell et al., 2010). Higher scores represent increased levels of anxiety and depression, with subscale scores above 11 indicating clinical significance. Cronbach's $\alpha = .76$.

Death Anxiety Scale (DAS)

The DAS (Templer, 1970) uses a fixed choice, true/false format to assess attitudes towards death on 15 items. The DAS is a brief measure, which has internal validity, test-retest reliability (Templer, 1970), and remains the most widely-used measure of death anxiety. Cronbach's α was .77. The DAS has been used in both palliative and non-palliative cancer populations (e.g. Gonen et al., 2012; Royal & Elahi, 2011), and has also been validated internationally in non-health populations (Nia et al., 2014). Higher scores indicate increased death anxiety, with a cut-off score of 7.

Data analyses

Time One: Preliminary analyses allowed for exploration and assumption checks¹⁴ to be carried out on the data, using IBM SPSS Statistics (version 22.0). Correlation analyses using Pearson's r were carried out to examine any relations between demographic and outcome variables, and between established predictor, response style, and outcome variables. Research aims 1 and 3 were met through the use of hierarchical multiple regression analyses, with aim 2 addressed through the use of moderation modelling, using PROCESS for SPSS (Hayes, 2013; Preacher & Hayes, 2008). Statistical tests were two-tailed with alpha set at .05. Variables which did not significantly correlate with at least one response style and one outcome variable were suppressed, i.e. excluded, from regression analyses, as suggested by Tabachnick and Fidell (2007). This condition and exclusion reduced the number of predictors in analyses and preserved statistical power¹⁵.

Time Two: Preliminary paired samples t -tests were carried out to establish whether any significant changes in scores had occurred between time points one and two. Aim 4 was met through the use of partial correlations, hierarchical multiple regression analyses,

¹⁴ For an overview of the assumption checks carried out, see EP 3.1

¹⁵ For details of the power calculation, see EP 3.2

and moderation modelling between time points one and two, with time one outcomes controlled for in each time two analysis. Cross-lag panel correlations of acceptance and outcome variable scores were carried out, to examine whether temporal and causal inferences could be drawn from the paths between data sets at two points in time.

Results¹⁶

Participant characteristics

At time one, 72 participants completed a battery of questionnaires, generating an attrition rate of 2.7%. The sample comprised 41 females, and 31 males (see Table 2). 58% of participants were over 50 years old, with a modal age range of 65-74 years. There was a wide range of cancer sites reported, the most common of which were: breast (28%), prostate (26%), bowel (13%), lung (10%) and 'other' (23%); the latter including blood, ovarian, neck, and pancreatic cancers. 75% of participants knew the stage of their cancer, and of these, 33.3% reported stage I or II cancers, and 41.6% reported stage III or IV. Stage I cancers are relatively small, and contained within the organ of origin, whereas stage II cancers are also contained, but are larger tumours. Contrastingly, stage III cancers are larger again, and may have started to spread to surrounding tissues. Stage IV cancers - 'metastases' – are defined as having spread to other organs in the body. 25% of participants reported having secondary cancers (stages 3 or 4), and 24% of participants had had cancer at least once before. 11 participants had previously taken part in other research, some of which investigated the psychological impact of survivorship. The most common attributions participants cited for having cancer were lifestyle factors, such as being overweight, having a poor diet, not exercising, and being stressed. At time two, a follow-up rate of 53% (n= 31) was obtained and calculated based on participants who had consented to the follow-up and went on to complete it. Three participants died between times one and two. Similar to the make-up of the time one sample, the most common cancers reported were breast (26%), prostate (16%), and blood (10%), with 23% of participants reporting secondary cancers, and 13% having experienced more than one episode of cancer. There were no significant differences between the demographic or clinical variables between time one and time two samples.

60% of the sample reported clinically significant levels of distress, as measured by HADS scores reaching 8 or above (Zigmond & Snaith, 1983), and 44% experienced high death anxiety, as measured on the Death Anxiety Scale, equalling or exceeding a cut-off score of 7. A further 31% of participants obtained scores of experiential avoidance in a range commensurate with clinically-relevant psychological distress, i.e. scores which exceed 24, when the AAQ II is scored in the direction of experiential avoidance (Bond et al., 2011).

¹⁶ For secondary data analyses, see EP 3.3 – 3.3.4

Sample demographics	Sample (N=72)	Percentage %
Gender	31	43.1
Male	41	56.9
Female		
Age range		
18-24	0	-
25-34	7	9.7
35-44	6	8.3
45-54	17	23.6
55-64	12	16.7
65-74	19	26.4
75+	11	15.3
Cancer site		
Unknown	3	4.2
Breast	19	26.4
Prostate	18	42.9
Other	12	16.7
Bowel	9	12.5
Lung	7	9.7
Blood	4	5.6
Secondaries	17	23.6
Cancer stage		
I	3	4.2
II	21	29.1
III	16	22.2
IV	14	19.4
Unknown	18	25.0
Highest level of education		
Missing	2	2.80
None	12	16.7
Level 1 or below	2	2.80
GCSE	17	24.0
A-Level	4	5.6
Higher Education or above	35	48.6
Religion/spirituality		
Yes	25	34.7
No	47	65.2
Number of previous cancers		
0	55	76.4
1	16	22.0
2 +	1	1.40

Table 2: Characteristics of the overall sample at time one

Time one: Correlational analyses

There were few significant correlations between variables used to capture the experience of having cancer (clinical and demographic factors), and response style or outcome variables (see Table 3). However, cancer appraisal scores, measured on the Brief IPQ, yielded seven significant positive correlations with avoidant response styles and outcome variables, e.g. disengagement, depression, and death anxiety ($r_s=.35-.54$, $p_s<.001$). Cancer appraisal was also negatively related to acceptance and emotional quality of life, and positively correlated with stage of cancer ($r_s = -.28-.28$, $p_s=.002-.037$). Earlier stage of cancer was associated with worse physical and functional quality of life ($r_s = -.27 - -.37$, $p_s=.005-.048$), but as cancer stage had no significant associations with response style variables, it was excluded from further analyses. Cancer appraisal was consequently retained as the measure of illness experience, due to being both an *a priori* variable of interest, and being significantly correlated with seven other variables. Cancer appraisal was therefore entered as the appraisal-focused predictor variable in subsequent regression analyses.

Five of the fourteen Brief COPE response styles measured were significantly associated with numerous outcomes and were subsequently entered as response style variables into regression analyses. The five retained response styles were self-distraction, denial, behavioural disengagement, venting, and self-blame, and can be broadly classified as 'avoidant' response styles. Each response style demonstrated significant correlations with lower acceptance, and greater anxiety, depression, death anxiety, and poorer quality of life ($r_s=-.06-.69$, $p_s=.042-<.001$). Overall, there were significant associations between higher rates of acceptance and more desirable outcomes across each outcome measure. Acceptance, as measured by the AAQ II, was positively and significantly associated with quality of life, and negatively associated with anxiety, death anxiety, and depression ($r_s=.26 - -.799$, $p_s=.031-<.001$).

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1=Stage		.283*	.007	-.039	-.134	.148	.226	.051	.254	-.061	.072	-.141	-.268*	-.372**	-.013
2=Brief IPQ			-.361**	.537**	.293*	.191	.208	.221	.503**	.437**	.204	-.257*	-.161	-.165	.353**
3=AAQ II				-.523**	-.400**	-.691**	-.279*	-.436**	-.601**	-.799**	.298*	.729**	.496**	.256*	-.571**
4=Disengagement					.524**	.326**	.373**	.184	.531**	.567**	-.154	-.554**	-.435**	-.319**	.284*
5=Venting						.309*	.106	.364**	.254*	.358**	-.177	-.286*	-.174	-.056	.242
6=Self-Blame							.439**	.415**	.418**	.619**	-.210	-.552**	-.394**	-.216	.503**
7=Denial								.007	.273*	.340*	-.096	-.377**	-.428**	-.243*	.275*
8=Self-distract									.247*	.486**	-.058	-.320**	-.115	.056	.313*
9=HADS Dep.										.501**	-.334**	-.573**	-.669**	-.589**	.325**
10=HADS Anx.											-.108	-.678**	-.394**	-.120	.662**
11=FACT-G Soc.												.326**	.456**	.292*	.000
12=FACT-G Emo.													.621**	.327**	-.461**
13=FACT-G Func.														.695**	-.225
14=FACT-G Phys.															-.003
15=DAS															

* $p < 0.05$, ** $p < 0.01$

Table 3: Time one bivariate correlation matrix between established predictor, response style, and outcome variables, which met the conditions for further analyses (with the exception of stage of cancer, displayed here for theoretical interest)

Note 1: Rows 1-2 = established predictor variables, 3-8 = response style variables, and 9-15 = outcome variables

Note 2: Variables with fewer than two significant correlations (one with a response and one with an outcome) were suppressed

Time one: Regression analyses

Seven, two-block hierarchical multiple regressions were run to determine whether cancer appraisal, acceptance, and avoidant response variables were significant explanatory variables of quality of life and psychological distress, in line with the primary research aim. Regression models were run in parallel, with each distress and quality of life outcome forming a dependent variable. Established predictor and response style variables were entered into the model in two blocks: block one without the AAQ II, and block two with the AAQ II. This allowed R^2 change scores to be calculated for the inclusion of the AAQ II into each model. The five avoidant response styles entered as predictors in the models were: self-distraction, denial, behavioural disengagement, venting, and self-blame. The response styles were entered if they had correlated with each outcome, though Brief IPQ and AAQ II scores were entered into all regressions as *a priori* variables of interest.

The results for each block of hierarchical regressions are displayed in Table 4. The addition of acceptance to block two models led to statistically significant increases in R^2 and F values for all models, except for physical and functional quality of life; though the addition of acceptance to these models did not cause significant reductions in R^2 ($p > .05$) or model significance. Conversely, the social quality of life model only reached significance following the addition of acceptance (increase in $R^2 = .10$, $F(1,68) = 7.80$, $p = .007$). Acceptance was the single most significant contributor to outcome in five models (out of seven) at time one, and explained between 3.1% and 10.8% of unique model variance, indicated by R^2 . In these models, acceptance had a significant relationship in a positive direction with emotional, and social quality of life, and significant relationship in a negative direction with depression, anxiety, and death anxiety. Cancer appraisals did not achieve significant explanatory power for any outcome.

Acceptance lacked significant explanatory power in two models, functional and physical quality of life, both of which were significantly explained by denial ($\beta_{\text{standardised}} = -.26$ - $-.32$, $ps = .014$ – $.034$). The direction of these beta values suggest that denial had a significant negative relationship with functional and physical quality of life outcomes. Only two further avoidant response styles were also significant contributors in two regression models: Behavioural disengagement was a significant contributor to depression, and self-distraction was a significant contributor to anxiety ($\beta_{\text{standardised}} = .19$ – $.43$, $ps = .020$ – $<.001$). However, acceptance also remained a significant explanatory variable in these models, and explained a larger proportion of variance for both depression and anxiety outcomes than either behavioural disengagement or self-distraction ($\beta_{\text{standardised}} = -.50$ - $-.53$, $ps < .001$).

Time one: Moderation analyses¹⁷

Using PROCESS (Preacher & Hayes, 2008) in SPSS, acceptance was examined as a moderator of the relationship between IPQ and each outcome variable, in parallel moderation models. There were no significant interaction effects of cancer appraisal and acceptance on any of the outcome variables ($p > .05$), suggesting that the effect of cancer appraisal on each outcome was not conditional on the level of acceptance. All main effects of acceptance on outcomes established in the multiple regressions remained, with many cancer appraisal effects reaching significance. However, no moderation

¹⁷ For an alternative approach to study design and data analysis, see EP 3.4

effects reached significance ($p > .05$), meaning the relationship between cancer appraisal, and quality of life and distress was not dependent on, or altered in strength or direction by, levels of acceptance.

Outcome variable and (n)	Block	Predictors entered	St. β	t	p	ΔR^2	df	F	p
HADS Depression (n=59)	1	IPQ	.147	1.273	.209	-	6,52	10.615	.000**
		Denial	.134	1.178	.244				
		Disengage	.543	4.011	.000**				
		Distract	.032	.307	.760				
		Self-blame	.148	1.236	.222				
		Venting	-.103	-.897	.374				
	2	AAQ II	-.528	4.025	.000**	.108**	1,51	14.073	.000**
		IPQ	.117	1.144	.258				
		Denial	.114	1.135	.262				
		Disengage	.429	3.507	.001**				
		Distract	-.061	-.647	.521				
		Self-blame	-.120	-.962	.341				
		Venting	-.134	-1.317	.194				
HADS Anxiety (n=61)	1	IPQ	.089	.917	.363	-	6,54	17.135	.000**
		Denial	.150	1.527	.133				
		Disengage	.290	2.553	.014*				
		Distract	.272	3.020	.004*				
		Self-blame	.394	3.848	.000**				
		Venting	-.053	-.540	.591				
	2	AAQ II	-.495	4.547	.000**	.097**	1,53	22.993	.000**
		IPQ	.073	.878	.384				
		Denial	.130	1.542	.129				
		Disengage	.170	1.684	.098				
		Distract	.190	2.390	.020				
		Self-blame	.141	1.359	.180				
		Venting	-.074	-.869	.389				

Outcome variable and (n)	Block	Predictors entered	St. β	t	p	ΔR^2	df	F	p
FACT-G Social (n=71)	1	IPQ	.003	.025	.980	-	1,69	.001	.980
	2	AAQ II	.344	-2.793	.007**	.103*	1,68	3.900	.025*
FACT-G Emotional (n=61)	1	IPQ	.127	1.033	.305	-	6,54	11.096	.000**
		Denial	-.152	-1.376	.175				
		Disengage	-.151	-1.351	.182				
		Distract	-.291	-2.250	.029*				
		Self-blame	-.121	-1.176	.245				
		Venting	-.392	-3.355	.001**				
	2	AAQ II	.111	.989	.327				
		IPQ	.473	-3.612	.001**		1,53	13.495	.000**
		Denial	-.137	-1.367	.177				
		Disengage	-.132	-1.302	.199				
FACT-G Functional (n=65)	1	Disengage	-.176	-1.454	.152	-	4,60	7.856	.000**
		Distract	-.042	-.438	.663				
		Self-blame	-.150	-1.198	.236				
		Venting	.131	1.281	.206				
	2	IPQ	-.101	-.803	.425	.031	1,59	7.059	.000**
		Denial	-.272	-2.227	.030*				
		Disengage	-.242	-1.830	.072				
		Self-blame	-.169	-1.433	.157				
		AAQ II	.269	-1.699	.095				
		IPQ	-.089	-.724	.472				
	2	Denial	-.261	-2.165	.034*				
		Disengage	-.163	-1.176	.245				
	2	Self-blame	-.017	-.114	.909				

Outcome variable and (n)	Block	Predictors entered	St. β	t	p	ΔR^2	df	F	p
FACT-G Physical (n=65)	1	IPQ	-.222	-1.690	.096	-	3,61	7.376	0.00**
		Denial	-.312	-2.598	.012*				
		Disengage	-.126	-.927	.357				
	2	AAQ II	.024	.178	.859	.000	1,60	5.452	.001**
		IPQ	-.223	-1.168	.097				
		Denial	-.318	-2.537	.014*				
DAS (n=63)	1	Disengage	-.136	-.922	.360	-	5,57	6.153	.000**
		IPQ	.037	.287	.775				
		Denial	.214	1.682	.098				
		Disengage	.064	.471	.639				
		Distract	.141	1.150	.255				
	2	Self-blame	.349	2.586	.012*	.067*	1,56	6.681	.000**
		AAQ II	-.410	2.531	.014*				
		IPQ	.031	.250	.803				
		Denial	.185	.250	.803				
		Disengage	-.054	1.517	.135				
		Distract	.065	-.394	.695				
		Self-blame	.151	.537	.594				

* $p < 0.05$, ** $p < 0.01$

Table 4: Two- block hierarchical multiple regression results for time one variables

Note: Only response style variables which significantly correlated with each outcome were entered in the models. Brief IPQ and AAQ II were entered into all models.

Time two analyses

t-tests between times one and two outcome variables (Table 5) were carried out as a preliminary check of whether variables had changed over time. *t*-tests revealed that outcome scores significantly changed over time on measures of anxiety, and on all four quality of life subdomains: emotional, social, physical, and functional. The direction of change showed that anxiety, emotional, and physical quality of life scores had significantly increased over time, whereas social and functional quality of life had decreased. Death anxiety and depression scores had also reduced between the two time points, but this finding did not reach significance. Scores were stable over time for illness appraisals and all response style variables ($p > .05$). No shifts in participants' demographic or clinical details were identified between times one and two, with the exception of three participants reporting a reduction in cancer stage, and two participants reporting an increase.

Outcome Variable	Time One		Time Two		<i>t</i> -test <i>p</i>
	Mean	<i>SD</i>	Mean	<i>SD</i>	
HADS Depression	3.77	3.45	3.50	2.24	.643
HADS Anxiety	6.94	3.84	8.55	4.29	.034*
FACT-G Social	16.73	5.91	10.17	7.61	.000**
FACT-G Emotional	16.32	4.71	19.30	2.81	.001**
FACT-G Functional	16.12	6.20	10.68	8.65	.004**
FACT-G Physical	21.30	4.92	26.43	1.92	.000**
DAS	6.47	3.21	5.80	2.93	.235

Table 5: *t*-test means and standard deviations for time one and two outcome variables

* $p < .05$, ** $p < .01$

Time two: Partial correlations and regression analyses

Partial correlations were carried out between the time one response styles that had previously emerged as significant (self-distraction, denial, behavioural disengagement, venting, and self-blame), and time two outcomes (Table 6). Two-block hierarchical regression analyses were then constructed in parallel models, regressing the significant time one response styles, identified in partial correlations, onto each time two outcome, whilst controlling for time one outcomes (Table 7). Time one Brief IPQ and AAQ II were entered into each model, as stated *a priori*. Time one predictors were entered in without the AAQ II in block one, and with the AAQ II in block two, again allowing for R^2 change scores to be calculated.

Time one acceptance was a significant explanatory predictor of future functioning, measured on two domains at time two: Anxiety and functional quality of life ($\beta_{\text{standardised}} = -.57$ -.49, $ps = .006$ -.012). The direction of these beta values was in line with time one regressions, with acceptance predictive of lower future anxiety, and higher future quality of life. Cancer appraisal was also a significant explanatory predictor of functional quality of life ($\beta_{\text{standardised}} = -.44$., $p = .020$), though acceptance made a greater contribution to the unique variance of this model than cancer appraisal, by a margin of 12% (difference in $R^2 = .12$). Self-distract, behavioural disengagement, and self-blame had been entered into regression models for anxiety, depression, and social quality of

life, and self-distract emerged as a significant explanatory predictor of future depression in a positive direction ($\beta_{\text{standardised}}=41$, $p=.018$), even when controlling for current levels of depression.

Time two: Moderation analyses

Moderation models were constructed for each of the seven outcome variables in parallel, i.e. anxiety, depression, death anxiety, and social, emotional, physical, and functional quality of life. Acceptance at time one was not a significant moderator in the interaction between illness perceptions and outcome at time two, for any of the quality of life or distress outcome variables.

Established predictor & response style variables: Time One

Outcomes: Time Two	Distract	Denial	Disengage	Venting	Self- blame	AAQ II	IPQ
HADS Depression T2	.528**	-.039	.195	.386	.208	-.340	-.232
HADS Anxiety T2	-.050	-.238	.396*	.235	-.413*	-.384	.083
DAS T2	.281	.289	.579**	.344	-.215	-.188	.521**
FAGT-G Physical T2	.023	-.065	.140	.224	.149	.051	-.125
FACT-G Social T2	-.419*	-.093	-.319	-.005	.016	.398	.006
FACT-G Emotional T2	.014	-.268	-.145	.039	.318	-.060	-.310
FACT-G Functional T2	-.363	.028	-.353	-.210	-.085	.469*	.265

* $p < 0.05$, ** $p < 0.01$. T2 = time two.

Table 6: Time two partial correlation matrix (controlling for time one outcome variables)

Note: Only response style variables which significantly correlated outcomes at time one were entered into the partial correlations

Outcome variables: Time Two and n	Block	Predictors entered: Time One	St. β	t	p	ΔR^2	df	F	p
HADS Depression 2 (n=29)	1	IPQ Distract	-.329 .405	-1.939 2.525	.064 .018*	-	2,25	6.236	.003**
	2	AAQ II IPQ Distract	-.191 -.316 .343	.925 -1.853 1.968	.364 .076 .061	.020	1,24	4.864	.005**
	1	IPQ Disengage Self-blame	-.100 .364 -.174	-.512 1.602 -.880	.614 .123 .388	-	3,23	4.587	.007**
HADS Anxiety 2 (n=28)	2	AAQ II IPQ Disengage Self-blame	-.567 -.093 .344 -.287	2.738 -.539 1.715 -1.602	.012* .595 .100 .124	.141*	1,22	6.205	.001**
	1	IPQ Distract	.089 -.097	.511 -.555	.614 .584	-	2,24	4.245	.015*
	2	AAQ II IPQ Distract	.347 .152 .019	-1.646 .876 .103	.113 .390 .919	.069	1,23	4.088	.012*
FACT-G Social 2 (n=28)	1	IPQ	-.331	-1.863	.073	-	1,27	5.063	.014*
	2	AAQ II IPQ	.151 -.332	-.737 -1.852	.467 .075	.015	1,26	3.500	.030*
FACT-G Emotional 2 (n=30)	1	IPQ	.354	1.796	.084	-	1,27	2.003	.154
	2	AAQ II	.484	-2.96	.006**	.220*	1,26	4.646	.010**

		IPQ	.437	2.483	.020*				
FACT-G Physical 2 (n=29)	1	IPQ	-.134	-.658	.516	-	1,26	1.390	.267
	2	AAQ II	.114	-.589	.561	.012	1,25	1.019	.401
		IPQ	-.108	-.511	.614				
DAS 2 (n=28)	1	IPQ	.251	1.496	.148	-	2,24	9.609	.000**
		Disengage	.322	1.900	.070				
	2	AAQ II	.014	-.087	.932	.000	1,23	6.911	.001**
		IPQ	.253	1.466	.156				
		Disengage	.325	1.842	.078				

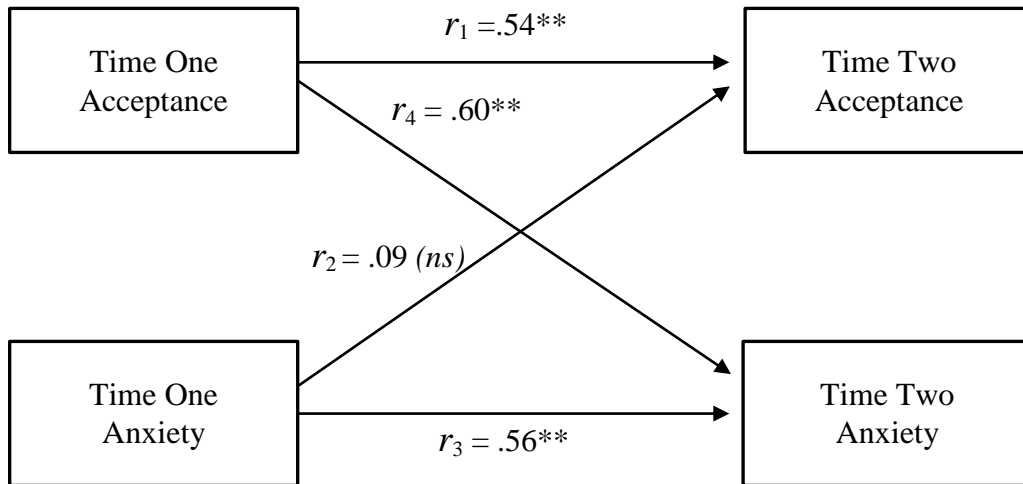
* $p < 0.05$, ** $p < 0.01$

Table 7: Two block hierarchical regression results for time two significant and outcome variables (controlling for time one outcome variables)

Note: Only response style variables which significantly correlated with each outcome were entered in the models. Brief IPQ and AAQ II were entered into all models.

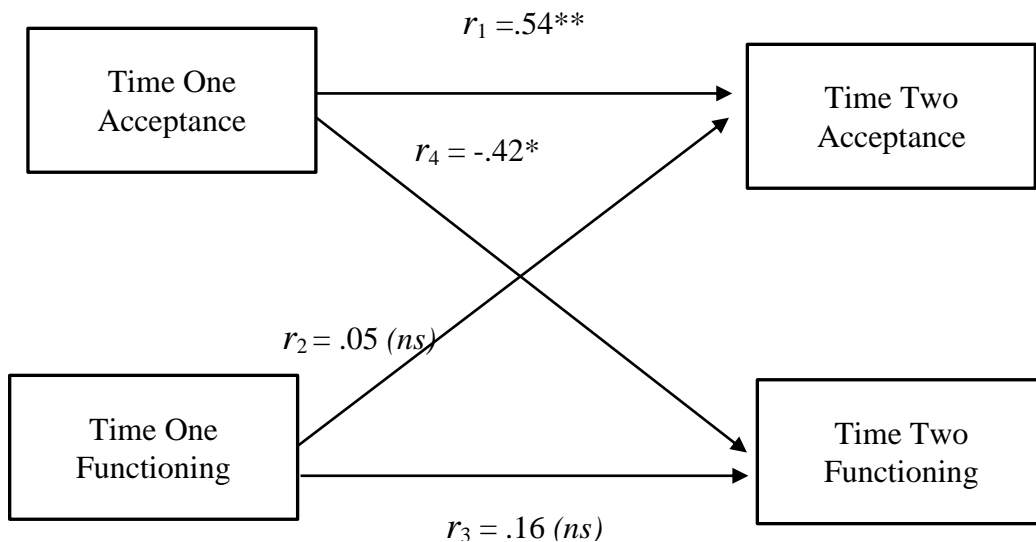
Cross-lag analyses

Cross-lag panel correlations (Figures 2 & 3), a method of examining the direction and relationship of change in longitudinal data (Selig & Little, 2012), revealed that acceptance at time one predicted both anxiety ($r=.60, p<.001$) and functional quality of life ($r=-.42, p=.024$) at time two. Furthermore, these were one-way predictive relationships, shown by one-way significant paths, as neither anxiety nor functional quality of life at time one significantly predicted acceptance at time two ($p>.05$). Cross-lag correlations with the five remaining outcomes yielded no significant findings, in either direction.



* $p<0.05$, ** $p<0.01$. *ns* = not significant

Figure 2: Path diagram for a two-variable panel model of acceptance and anxiety, at times one and two



* $p<0.05$, ** $p<0.01$. *ns* = not significant

Figure 3: Path diagram for a two-variable panel model of acceptance and functioning (FACT-G functional), at times one and two

Discussion

This longitudinal quantitative study aimed to explore whether acceptance was related to quality of life and distress in cancer patients, alongside other response styles. It also aimed to explore whether acceptance functioned as a moderator variable and an approach response style over time. Avoidant response styles –such as denial, behavioural disengagement, and self-distraction – showed a pattern of moderate to strong negative correlations with quality of life, and significant positive correlations with distress outcomes in the cancer population¹⁸. Cancer appraisals lacked overall explanatory power, but did achieve a greater number of significant correlations with response styles and outcomes than measures of physical disease characteristics. In line with previous research, this supports the role of more threatening cognitive appraisals in poorer outcomes; relationships that were not demonstrated by disease characteristics alone. Contrastingly, acceptance was an independent explanatory variable of quality of life and distress outcomes, in directions consistent with psychological health. Acceptance also demonstrated predictive power for these outcomes over time, over and above the influence of cancer appraisals.

Theoretical implications¹⁹

In contrast to the ‘protective’ and defensive role of denial posited by TMT, denial was significantly associated with lower quality of life, and higher distress; including on the measure of death anxiety. TMT suggests that denial should be utilised to avoid the terror of mortality and its associated emotions, yet here the findings that denial was significantly associated with distress and poorer quality of life suggest the opposite.

Quality of life declined over time on social and functional domains, the latter of which was initially significantly explained by denial. Avoidant responses were therefore implicated in poorer functional quality of life, over and above the appraisal of cancer, which initially correlated with stage of cancer and may in part reflect some objective disease severity. Functional and social quality of life both declined over time, despite physical quality of life improving, lending support to the ACT notion that experiential avoidance at the cost of engagement in valued action may be detrimental to maintaining distress, irrespective of physical disease status.

The results provide preliminary support for the trial of acceptance-based interventions in a cancer population, having shown that acceptance was significantly more implicated in optimal quality of life and distress outcomes than other response styles. This included those that might be targeted in conventional therapies, such as CBT, which is currently the most empirically-supported psychological intervention for cancer patients. Moreover, some non-accepting, avoidant response styles –those which have been hypothesised by TMT theorists to be protective when faced with a proximal threat such as cancer – were found to be inversely related to quality of life, and positively associated with distress in this population. Denial, a traditional death-avoidance strategy, was uniquely implicated in explaining more outcomes than any other avoidant response style measured, even when included alongside acceptance; which had absorbed the explanatory variance of other responses in some models. The direction of

¹⁸ For results in the context of theory, see EP 4.2 – 4.2.4

¹⁹ For implications for clinical knowledge and practice, see EP 4.3

these explanatory relationships was positively related to distress, and negatively related to quality of life.

ACT's principle that experientially avoiding and struggling against inner experiences maintains distress is supported, given that avoidant responses were consistently associated with poorer outcomes. Acceptance was a unique predictor of outcomes in the opposite direction, suggesting that acceptance may be a viable, alternative response strategy for influencing quality of life and distress. However, given that many response styles did not retain significant explanatory power following the addition of the acceptance measure, it is also likely that avoidant responses and experiential avoidance (as measured by low AAQ II scores) share some common variance, and that this prevented avoidant response styles from achieving significance. Experiential avoidance may therefore be a generalised avoidance phenomenon, rather than a unique concept, given its medium to large correlations with other measures of avoidant responding (Chawla & Ostafin, 2007). Acceptance, however, as measured by the AAQ II, made a unique and statistically independent contribution as an explanatory variable: accounting for an additional 3-10% of model variance, over and above cancer appraisals or avoidant response styles.

Clinical implications

Of particular clinical relevance is the long-term, deleterious effect of avoidance on outcomes over time, which continues even when avoidant responses themselves remain stable. Furthermore, levels of acceptance are predictive of future functioning and anxiety in a uni-directional relationship, which tentatively suggests that an accepting response style may drive outcomes, in a one-way relationship. An implication of this for future research and practice is that acceptance predicts and potentially influences future functioning, such that it may form a useful target for intervention. However, it must be noted that the relationships in this study were calculated using aggregate scores, and that within the sample there may be considerable individual differences. It cannot be stated that acceptance and avoidance are entirely helpful or unhelpful for all participants, as participants were not individually categorised based on their response styles and corresponding outcomes scores. A further caveat for intervention, which may facilitate the need for preliminary trials, is that acceptance was not manipulated in this study. Thus, although acceptance is strongly implicated in improved outcomes, even over time, it remains to be seen whether changing acceptance will lead to changes in outcomes, particularly given the potentially moderating effects of pre-existing response styles on outcomes.

Strengths & Limitations²⁰

This study used a broad sample of cancer patients, and was conducted over two points in time. Although there is not yet a vast body of literature focusing on ACT processes in cancer patients, those that do exist have often used narrow cancer sub-groups and cross-sectional designs. Whilst this study acknowledged that different cancer groups may have differing needs and levels of distress, and that this often guides study design by way of improving generalisability to unique sub-populations, this study deliberately targeted a large sample. ACT models of psychological health and psychopathology, and the purported advantage of acceptance, are generalisable and universal, rather than theorised to be unique to specific individuals or types of cancer. The broad sample in

²⁰ For further strengths and limitations, see EP 4.4 – 4.4.3

this study represented groups of cancer patients as a whole, in line with an underlying theory of acceptance and widespread experiential avoidance, which Hayes et al. (2011) attribute to a category as broad as human nature. Furthermore, distress and threatening cancer appraisals occurred across all sub-sections of this sample, suggesting that these factors may have a generalised effect, which is perhaps unsurprising given that cancer appraisals are not uniquely related to objective disease status, and also given the complex and wide-reaching effects cancer can have on people's lives.

Limitations of this study include the observational research design, and the cross-sectional nature of the data collected at time-one, which was consequently subject to the limitations of correlational, multivariate data analyses and the non-causal conclusions that can be drawn from them. Multiple regression models are not capable of establishing causal inferences or temporality between data at a single point in time, yet despite this some researchers use multiple regressions to make predictions about future performance, which is not a valid conclusion when carried out within a cross-sectional research design. The inclusion of data at a second time point went some way to addressing these limitations however, as multiple regressions, moderation, and cross-lag models were carried out on data taken from two points in time, thus increasing their predictive validity, and effectively demonstrating one-directional predictive relationships. A further limitation of this study was that questionnaires are inherently reliant upon self-report, which can introduce subjective and social desirability biases, and produce common method variance in the data; though again the latter was addressed through the inclusion of a follow-up point. Although the response rate achieved for the follow-up was over half, at 53%, this sample had opted-in and were therefore somewhat self-selecting, which introduced a further risk of bias in terms of the characteristics and response styles of the follow-up group.

Time since diagnosis was not accurately captured, as it has been elsewhere in cancer literature (e.g. Hulbert-Williams et al., 2015). Furthermore, the Brief IPQ achieved a very low score for internal reliability ($\alpha=.38$), yet has achieved much higher levels in cancer research elsewhere (e.g. Ashley et al., 2013). This alpha level may have been decreased by the adaptation of the items to suit the population, as recommended by the authors to increase the scale's face and content validity for different illness populations (Broadbent et al., 2015). However, authors have cautioned against the use of Cronbach's alpha as a standalone measure of internal reliability, at the expense of study context (Sijtsma, 2009; Pedhazur & Schmelkin, 1991). It is possible that the low alpha for Brief IPQ was both affected by re-wording of certain questions to make them cancer-specific, and also that it reflects the complex nature of illness appraisal. A further measurement limitation may be posed by the use of the AAQ II, as some researchers have questioned whether its items are conflated with distress outcomes (Wolgast, 2014). Although the AAQ II was used as a process measure indicative of acceptance, with implications for targeted assessment and intervention in this process, the observed relationships with outcomes may be artificially inflated by overlapping content and weak discriminant construct validity. However, use of the AAQ II is well-established in the ACT literature, and it has been deemed to be of satisfactory reliability and validity in research with cancer populations (Feros, Lane, Ciarrochi, & Blackledge, 2013). At the time of this study, no superior psychometric measure of acceptance was available.

Finally, moderation analyses were carried out using only acceptance as a proposed moderator. This was because acceptance was the primary variable of interest in this study, but also in part to prevent the increased risk of finding chance effects. Although data was captured at two points in time, this was without any psychological intervention having taken place in the interim period. Future research²¹ could show whether an ACT intervention might result in a change to the stability of acceptance that had been demonstrated in this study over three months in time. Intervention across multiple time points would also justify the use of mediational analyses, to see whether acceptance or other response styles explained any relationship between cancer appraisals and psychological outcomes.

*Conclusions*²²

Acceptance is supported as a helpful response style, and a potential target for intervention in psychological work with cancer patients. This is over and above the targeting of cancer appraisals, which had less predictive and explanatory power, though remained correlated with distress outcomes. Furthermore, results also show that many response styles that might be incorporated into more traditional CBT or expressive therapies are not associated with positive outcomes in cancer patients. Such strategies, as measured by the Brief COPE, include active coping, emotional support, planning, positive reframing, and venting. Finally, as experiential avoidance and avoidant response styles had greater predictive power than cancer appraisal, increasing acceptance and shifting relationships to distressing cognitions, rather than their content, is indicated as a direction for possible intervention studies with this population.

²¹ For future research, see EP 4.5

²² For personal reflections, see EP 4.6 – 4.6.3

References

- Adelbratt, S., & Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. *Palliative Medicine*, 14(6), 499-507.
- Angiola, J. E., & Bowen, A. M. (2013). Quality of life in advanced cancer an acceptance and commitment therapy view. *The Counseling Psychologist*, 41(2), 313-335.
- Ashley, L., Smith, A. B., Keding, A., Jones, H., Velikova, G., & Wright, P. (2013). Psychometric evaluation of the revised illness perception questionnaire (IPQ-R) in cancer patients: Confirmatory factor analysis and rasch analysis. *Journal of Psychosomatic Research*, 75(6), 556-562.
- Barraclough, J. (1999). *Cancer and emotion: A practical guide to psycho-oncology*. New York: John Wiley & Sons.
- Bill-Axelson, A., Garmo, H., Lambe, M., Bratt, O., Adolfsson, J., Nyberg, U., . . . Stattin, P. (2010). Suicide risk in men with prostate-specific antigen-detected early prostate cancer: A nationwide population-based cohort study from PCBaSe sweden. *European Urology*, 57(3), 390-395.
- Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., . . . Zettle, R. D. (2011). Preliminary psychometric properties of the acceptance and action Questionnaire-II: A revised measure of psychological inflexibility and experiential avoidance. *Behavior Therapy*, 42(4), 676-688.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637.
- Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the brief illness perception questionnaire. *Psychology & Health*, 30(11), 1361-1385.

- Cancer Research UK. (2014). *Cancer risk statistics*. London: Cancer Research UK.
Retrieved from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk>
- Cardy, P., Corner, J., Evans, J., Jackson, N., Shearn, K., & Sparham, L. (2006). *Worried sick: The emotional impact of cancer*. Retrieved from: <http://www.macmillan.org.uk/documents/aboutus/commissioners/macmillansupportlineanevidencereview2012.pdf>
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine*, 4(1), 92-100.
- Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., . . . Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65(2), 375.
- Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., . . . Brannon, J. (1993). The functional assessment of cancer therapy scale: Development and validation of the general measure. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 11(3), 570-579.
- Ciarrochi, J., Fisher, D., & Lane, L. (2011). The link between value motives, value success, and well-being among people diagnosed with cancer. *Psycho-Oncology*, 20(11), 1184-1192.
- Davis, M. L., Morina, N., Powers, M. B., Smits, J. A. J., & Emmelkamp, P. M. G. (2014). A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychotherapy and Psychosomatics*, 84(1), 30-36.
- Dunne, S., Mooney, O., Coffey, L., Sharp, L., Desmond, D., Timon, C., . . . Gallagher, P. (2016). Psychological variables associated with quality of life following primary treatment for head and neck cancer: A systematic review of the literature from 2004 to 2015. *Psycho-Oncology*. Advance online publication. doi: 10.1002/pon.4109

- Feros, D. L., Lane, L., Ciarrochi, J., & Blackledge, J. T. (2013). Acceptance and commitment therapy (ACT) for improving the lives of cancer patients: A preliminary study. *Psycho-Oncology*, 22(2), 459-464.
- Gao, W., Bennett, M. I., Stark, D., Murray, S., & Higginson, I. J. (2010). Psychological distress in cancer from survivorship to end of life care: Prevalence, associated factors and clinical implications. *European Journal of Cancer*, 46(11), 2036-2044.
- Gillanders, D., Ferreira, N., Bose, S., & Esrich, T. (2013). The relationship between acceptance, catastrophizing and illness representations in chronic pain. *European Journal of Pain*, 17(6), 893-902.
- Gillanders, D. T., Sinclair, A. K., MacLean, M., & Jardine, K. (2015). Illness cognitions, cognitive fusion, avoidance and self-compassion as predictors of distress and quality of life in a heterogeneous sample of adults, after cancer. *Journal of Contextual Behavioral Science*, 4(4), 300-311.
- Gonen, G., Kaymak, S. U., Cankurtaran, E. S., Karslioglu, E. H., Ozalp, E., & Soygur, H. (2012). The factors contributing to death anxiety in cancer patients. *Journal of Psychosocial Oncology*, 30(3), 347-358.
- Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The causes and consequences of a need for self-esteem: A terror management theory. In R.F. Baumeister (Ed.), *Public self and private self* (pp. 189-212). Germany: Springer.
- Hall, C. (2011). Beyond kubler-ross: Recent developments in our understanding of grief and bereavement. *InPsych: The Bulletin of the Australian Psychological Society Ltd*, 33(6), 8.
- Harris, R. (2006). Embracing your demons: An overview of acceptance and commitment therapy. *Psychotherapy in Australia*, 12(4), 70.
- Hayes, S., Strosahl, K., & Wilson, K. (2011). *Acceptance and commitment therapy: An experiential approach to behavior change* (2nd ed.). New York: Guilford Press.

- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.
- Hayes, S., & Smith, S. (2005). *Get out of your mind and into your life*. Oakland, CA: Raincoast Books.
- Hoelter, J. W. (1979). Multidimensional treatment of fear of death. *Journal of Consulting and Clinical Psychology*, 47(5), 996.
- Hulbert-Williams, N. J., & Storey, L. (2015). Psychological flexibility correlates with patient-reported outcomes independent of clinical or sociodemographic characteristics. *Supportive Care in Cancer*, 24(6), 2513-2521.
- Hulbert-Williams, N., Storey, L., & Wilson, K. G. (2015). Psychological interventions for patients with cancer: Psychological flexibility and the potential utility of acceptance and commitment therapy. *European Journal of Cancer Care*, 24(1), 15-27.
- Jacob, M. C., Kerns, R. D., Rosenberg, R., & Haythornthwaite, J. (1993). Chronic pain: Intrusion and accommodation. *Behaviour Research and Therapy*, 31(5), 519-527.
- Jim, H. S., & Andersen, B. L. (2007). Meaning in life mediates the relationship between social and physical functioning and distress in cancer survivors. *British Journal of Health Psychology*, 12(3), 363-381.
- Kashdan, T. B., & Rottenberg, J. (2010). Psychological flexibility as a fundamental aspect of health. *Clinical Psychology Review*, 30(7), 865-878. doi:<http://dx.doi.org/10.1016/j.cpr.2010.03.001>
- Low, J., Serfaty, M., Davis, S., Vickerstaff, V., Gola, A., Omar, R. Z., . . . Turner, K. (2016). Acceptance and commitment therapy for adults with advanced cancer (CanACT): Study protocol for a feasibility randomised controlled trial. *Trials*, 17(1), 1.

- Luckett, T., King, M. T., Butow, P. N., Oguchi, M., Rankin, N., Price, M. A., . . . Heading, G. (2011). Choosing between the EORTC QLQ-C30 and FACT-G for measuring health-related quality of life in cancer clinical research: Issues, evidence and recommendations. *Annals of Oncology : Official Journal of the European Society for Medical Oncology/ESMO*, 22(10), 2179-2190. doi:10.1093/annonc/mdq721
- McCracken, L. M. (1998). Learning to live with the pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain*, 74(1), 21-27.
- McCracken, L. M. & Eccleston, C. (2003). Coping or acceptance: what to do about chronic pain? *Pain*, 105, 197-204.
- Mitchell, A. J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C., & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *The Lancet Oncology*, 12(2), 160-174.
- Mitchell, A. J., Meader, N., & Symonds, P. (2010). Diagnostic validity of the hospital anxiety and depression scale (HADS) in cancer and palliative settings: A meta-analysis. *Journal of Affective Disorders*, 126(3), 335-348.
- Mosher, C. E., & Danoff-Burg, S. (2007). Death anxiety and cancer-related stigma: A terror management analysis. *Death Studies*, 31(10), 885-907.
- National Institute for Clinical Excellence. (2004). *Improving supportive and palliative care for adults with cancer: The manual*. National Institute for Clinical Excellence. London: Author.
- Neel, C., Lo, C., Rydall, A., Hales, S., & Rodin, G. (2015). Determinants of death anxiety in patients with advanced cancer. *BMJ Supportive & Palliative Care*, 5(4), 373-380. doi:10.1136/bmjspcare-2012-000420
- Ng, T. S. (2012). Brief illness perception questionnaire (brief IPQ). *Journal of Physiotherapy*, 58(3), 202.

- Nia, H. S., Ebadi, A., Lehto, R. H., Mousavi, B., Peyrovi, H., & Chan, Y. H. (2014). Reliability and validity of the persian version of templer death anxiety scale-extended in veterans of Iran–Iraq warfare. *Iranian Journal of Psychiatry and Behavioral Sciences*, 8(4), 29.
- Nipp, R. D., El-Jawahri, A., Fishbein, J. N., Eusebio, J., Stagl, J. M., Gallagher, E. R., . . . Greer, J. A. (2016). The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer*, 122(13): 2110-2116.
- Pedhazur, E. & Schmelkin, L. P. (1991). *Measurement, design, and analysis: An integrated approach*. London: Psychology Press.
- Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods*, 40(3), 879-891.
- Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology*, 80(6), 1007.
- Price, A., Goodwin, L., Rayner, L., Shaw, E., Hansford, P., Sykes, N., . . . Lee, W. (2012). Illness perceptions, adjustment to illness, and depression in a palliative care population. *Journal of Pain and Symptom Management*, 43(5), 819-832.
- Ramachandra, P., Booth, S., Pieters, T., Vrotsou, K., & Huppert, F. A. (2009). A brief self-administered psychological intervention to improve well-being in patients with cancer: Results from a feasibility study. *Psycho-Oncology*, 18(12), 1323-1326.
- Rand, K. L., Cripe, L. D., Monahan, P. O., Tong, Y., Schmidt, K., & Rawl, S. M. (2012). Illness appraisal, religious coping, and psychological responses in men with advanced cancer. *Supportive Care in Cancer*, 20(8), 1719-1728.
- Rinaldis, M., Pakenham, K. I., Lynch, B. M., & Aitken, J. F. (2009). Development, confirmation, and validation of a measure of coping with colorectal cancer: A longitudinal investigation. *Psycho-Oncology*, 18(6), 624-633.

- Royal, K. D., & Elahi, F. (2011). Psychometric properties of the death anxiety scale (DAS) among terminally ill cancer patients. *Journal of Psychosocial Oncology*, 29(4), 359-371.
- Selig, J.P. & Little, T.D. (2012). Autoregressive and cross-lagged panel analysis for longitudinal data. In B. Laursen, T.D. Little & N.A. Card (Eds.), *Handbook of Developmental Research Methods* (pp. 265-279). New York: Guilford Press.
- Sijtsma, K. (2009). On the use, the misuse, and the very limited usefulness of Cronbach's alpha. *Psychometrika*, 74(1), 107-120.
- Solomon, S., Greenberg, J., & Pyszczynski, T. (2015). *The worm at the core: On the role of death in life*. London: Random House.
- Šoštarič, M., & Šprah, L. (2004). Psychological distress and intervention in cancer patients treated with radiotherapy. *Radiology and Oncology*, 38(3)
- Stanton, A. L., Kirk, S. B., Cameron, C. L., & Danoff-Burg, S. (2000). Coping through emotional approach: Scale construction and validation. *Journal of Personality and Social Psychology*, 78(6), 1150.
- Stanton, A. L. (2012). What happens now? Psychosocial care for cancer survivors after medical treatment completion. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology*, 30(11), 1215-1220. doi:10.1200/JCO.2011.39.7406
- Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed). Boston: Allyn & Bacon.
- Templer, D. I. (1970). The construction and validation of a death anxiety scale. *The Journal of General Psychology*, 82, 165-177.
- Tolstikova, K., Fleming, S., & Chartier, B. (2005). Grief, complicated grief, and trauma: The role of the search for meaning, impaired self-reference, and death anxiety. *Illness, Crisis & Loss*, 13(4), 293-313.

- Tomer, A., & Eliason, G. (1996). Toward a comprehensive model of death anxiety. *Death Studies*, 20(4), 343-365.
- Van Oort, L., Schröder, C., & French, D. (2011). What do people think about when they answer the brief illness perception questionnaire? A 'think-aloud' study. *British Journal of Health Psychology*, 16(2), 231-245.
- Vilardaga, R., Hayes, S. C., Atkins, D. C., Bresee, C., & Kambiz, A. (2013). Comparing experiential acceptance and cognitive reappraisal as predictors of functional outcome in individuals with serious mental illness. *Behaviour Research and Therapy*, 51(8), 425-433. doi:10.1016/j.brat.2013.04.003
- Vodermaier, A., Linden, W., MacKenzie, R., Greig, D., & Marshall, C. (2011). Disease stage predicts post-diagnosis anxiety and depression only in some types of cancer. *British Journal of Cancer*, 105(12), 1814-1817.
- Vodermaier, A., Linden, W., & Siu, C. (2009). Screening for emotional distress in cancer patients: A systematic review of assessment instruments. *Journal of the National Cancer Institute*, 101(21), 1464-1488. doi:10.1093/jnci/djp336
- Webster, K., Cella, D., & Yost, K. (2003). The functional assessment of chronic illness therapy (FACIT) measurement system: Properties, applications, and interpretation. *Health and Quality of Life Outcomes*, 1, 79. doi:10.1186/1477-7525-1-79
- Wolgast, M. (2014). What does the acceptance and action questionnaire (AAQ-II) really measure? *Behavior Therapy*, 45(6), 831-839.
- Yusoff, N., Low, W., & Yip, C. (2010). Reliability and validity of the brief COPE scale (English version) among women with breast cancer undergoing treatment of adjuvant chemotherapy: A malaysian study. *Medical Journal of Malaysia*, 65(1), 41-44.
- Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10(1), 19-28.

- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.
- Zimmermann, C. (2012). Acceptance of dying: A discourse analysis of palliative care literature. *Social Science & Medicine*, 75(1), 217-224.

EXTENDED PAPER

1. Extended background

1.1. Measuring Distress and Quality of Life in Cancer

1.1.1. Operationalising Distress

In order to attempt effective measurement of distress and quality of life in a cancer population, it is first important to discuss the meaning of these terms. Distress is a broad construct that is often poorly-defined (Ridner, 2004), and is therefore open to subjective interpretation, potentially meaning different things to different people, and adversely affecting the reliability of outcomes. Within the context of this research, distress is taken to mean adverse emotional and psychological “functioning in the face of stressful life events” (Abeloff, Armitage, Lichter, & Niederhuber, 2000, p.556). Distress was consequently measured by rating scales for anxiety, depression, and death anxiety, which were framed within an illness context through prefacing in the questionnaire, and also in the participant information sheet. Distress is therefore used only as an overarching term, to refer to these individual outcome measures as an aggregated category of outcome measures.

Quality of life has been defined as ‘a complete state of physical, mental, and social well-being, not merely the absence of disease’ (World Health Organization, 1997). Measuring and improving quality of life, rather than focusing solely on distress and how to reduce it, is therefore congruent with both ACT philosophy, and also the recognised need from within the oncology community to promote wellbeing, rather than just to reduce symptoms of distress (Jacobsen & Jim, 2008). In this study, quality of life was studied in relation to cancer, as measured by the FACT-G (Cella et al., 1993).

1.1.2. Methodological Challenges of Measuring Distress

Operationalising psychological distress for the purposes of measurement in research studies has in many cases relied on psychiatric diagnoses from the Diagnostic and Statistical Manual (5th ed.; DSM-V; American Psychiatric Association, 2013), or International Classification of Diseases (10th ed.; ICD-10; World Health Organisation, 1992), rather than on self-reported measurement (e.g. Bukberg, Penman & Holland, 1984). This method risks excluding patients’

distress where it is not severe enough to meet diagnostic thresholds, and also relies upon the methodological robustness of diagnostic classification systems. The validity, reliability, and even utility of such systems have been refuted by numerous researchers (e.g. Kinderman, Read, Moncrieff, & Bentall, 2013; Pickersgill, 2013). Diagnoses were not required in this study design, in part because of the observational nature of the study and the lack of need to randomise participants to different conditions, or select suitable participants for a certain intervention; occasions when diagnoses have some practical utility. In this study, all outcome measures used were self-report questionnaires of psychological distress and cancer-related quality of life, which were non-diagnostic and of greater relevance to the cancer context and psychological, rather than psychiatric, models of behaviour and functioning (Herschbach et al., 2004). Furthermore, ACT researchers have been openly critical of psychiatric diagnoses and classification systems, stating that symptoms and signs can emerge through experiential avoidance rather than biological causation (Hayes et al., 2013), and also implying that research should focus on functional analyses and underlying psychological processes, rather than merely labelling behaviours as the result of disease.

Although the prevalence of emotional distress within cancer populations is thought to be as high as 75% (Macmillan, 2015), measuring this accurately and effectively poses some methodological challenges, which could limit the validity and generalisability of such prevalence estimates. For example, cancer affects a very broad number of areas in people's lives, such as physical health symptoms, treatment side-effects, financial worries, concerns about leaving work, and diminishing social engagement. The variability in these factors between individuals adds to the challenge of measuring distress prevalence, as cancer-related distress could therefore be influenced by, and interpreted to mean, a vast range of factors which vary between individuals. Multi-dimensional measures of quality of life have attempted to reflect this challenge by including subscales for different areas of life, for example the FACT-G measure (Cella et al., 1993), which has scales on physical, functional, social, and emotional domains. Recently, the Distress Thermometer (National Comprehensive Cancer Network, 2007) was introduced as a rapid distress-screening tool for cancer

patients. Whilst clinician awareness and screening of distress in cancer patients is to be commended, the simplicity of the rating scale measure may fail to accurately measure or capture the complexity of the factors affecting the population, as outlined previously. The Distress Thermometer has consequently been criticised for lacking validity (Stewart-Knight, Parry, Abey, & Seymour, 2012), and is perhaps not specific enough in terms of defining what 'distress' means. Relying on one single item measure such as the Distress Thermometer, to accurately depict distress and quality of life in this population is therefore unlikely to reflect the diverse and broad experiences of cancer patients when used as a standalone measure in research studies. However, the distress thermometer may have some utility as a tool for beginning conversations about subjective emotional distress in clinical settings –conversations that may otherwise not occur– and should be used as part of a more extensive psychological assessment as necessary (Gessler et al., 2008; Hegel et al., 2008).

Beyond having to administer a broad range of measures in an attempt to capture the complex and multiple factors which can influence distress in cancer patients, other challenges to measuring distress include the heterogeneity of the population, due to the variance in disease factors such as cancer stages and sites. There are also broad methodological differences between existing research studies carried out, and the settings in which research projects are conducted (Massie, 2004). Furthermore, distress is not a stable factor and is likely to fluctuate across time, with the illness trajectory, levels of pain, treatment side-effects, or cancer re-occurrence (Massie 2004; Stanton, Leucken, MacKinnon, & Thompson, 2012); as well as distress potentially being influenced by problems which pre-dated the disease. This latter possibility is hard to exclude, and presents the potential for confounding variables, which may also influence outcomes. Distress can also continue into remission, and may be linked to threats of re-occurrence and shortened life-expectancy (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006), yet along with palliative patients, these two cancer sub-groups are not well-researched (Payne, 1992). This affects the overall generalisability of findings to both past and terminal cancer patients, given that these sub-populations may have unique concerns related to

survivorship, or higher levels of distress related to the imminent end of life (Adelbratt & Strang, 2000). This study attempted to address some of the concerns about specific cancer populations by recruiting from a broad section of the cancer population, and also included a follow-up in order to capture data at more than one point in time, or in a person's disease trajectory. For further details about methodological decisions and rationale, see extended paper 2.2 – 2.3.

1.2. Death Anxiety, ACT, and TMT

1.2.1. Death Anxiety in Avoidant Society

Given that all humans know rationally they will one day die, fear about death may be present in the general population (Yalom, 2008), but is reportedly higher amongst people with chronic diseases (Strömberg & Jaarsma, 2008). Even though increasing numbers of cancer patients are surviving (Cancer Research UK, 2014), cancer still poses a very real threat to life, and it makes intuitive sense that cancer is therefore associated with death and dying. This association is perhaps enhanced by the amount of coverage cancer is afforded in Western society, via charity advertisements, or through the media reporting breakthroughs in medical treatments for cancer, sending a hopeful message that we can postpone death.

Given that for many, cancer is becoming more akin to a chronic disease as treatments and prognoses continually improve (Rand et al., 2012), this raises questions about the impact of lengthier diseases upon psychological factors, such as general anxiety and death anxiety. In theoretical terms, the proximal threat, or life event, of cancer represents a change in context, whereby habitual ways of responding may no longer be helpful nor effective at minimising anxiety. Anxiety in cancer patients is well-reported and frequently measured as a key factor in distress. However, intrusive and unpleasant thoughts may often involve disease, death, or disability (Stark & House, 2000), yet specific death anxiety is far rarer in the literature on distress in this population (Gonen et al., 2012). Kübler-Ross (1969) stated that the drive to avoid death prevents an open dialogue in society and in healthcare. Given that society, and even clinicians,

may be anxious about talking about dying (Peters et al., 2013), it may be that patients are not asked about their experiences on this domain, or are asked instead about other anxiety-eliciting factors; thereby talking about anxiety, but not in relation to death. Death anxiety is demonstrated and potentially reinforced in many ways throughout Western society, and is notably lower in Eastern countries (Urien & Occidentale, 2004), where religions such as Hinduism view death as the first element in life, and believe in life after death. Such views can prevent death from being seen as a frightening entity, and in turn affect how cultures behave around the dying; suggesting that reappraisal or acceptance of death may reduce anxiety. It is interesting to reflect on whether European countries, where there is a trend towards atheism (Eurobarometer, 2005), are more avoidant towards death as a result of not utilising religion as a potential defence mechanism to prevent experiencing death anxiety.

1.2.2. Death Anxiety: Theoretical Underpinnings

One reason we may fear death is because it is associated with painful emotions, such as grief and sadness; emotions reported whether we are grieving for ourselves, prior to dying, or for others (Hoëlter, 1979; Kübler-Ross, 1969). According to ACT, attempting to avoid these inner feelings will only serve to increase their salience, and thereby feelings in relation to death remain strong. Furthermore, thoughts, feelings, and inner experiences which are struggled against are increasingly elicited by an augmenting number of death-related and emotion-eliciting stimuli.

Theoretically, ACT and TMT differ in their understandings of how this relationship between cancer and anxiety might have come to pass. TMT posits that death anxiety is an evolutionary trait universal to humanity, whereby we are driven to stay alive and would be psychologically paralysed by conscious death awareness (Iverach, Menzies, & Menzies, 2014). Within this model, behaviours, either at a societal level, such as social engagement, or at an intrapsychic level, such as denial and thought-suppression, are interpreted as being motivated by the underlying fear of death. Many experimental studies have shown the results of death-reminding primers upon subsequent behaviours, such as with people who had been reminded of mortality then demonstrating increased defensive

and avoidant behaviours, both intrapsychically and towards others (e.g. Solomon, Greenberg, & Pyszczynski, 2015). However, it could also be interpreted that these studies have shown a link between the priming of anxiety, and ensuing avoidance; which may indeed be a helpful and adaptive response style in the short-term (Suls & Fletcher, 1985), as most people are not overly reminded of death on a frequent basis. However, in the life-threatening context of receiving a diagnosis of cancer, such avoidance may cease to be adaptive or successful. This is because of the potential for death and illness reminders to increase exponentially, for example on visits to hospital, when receiving treatment, and when experiencing physical symptoms or side-effects. The long-term effects of avoidant response styles upon distress and quality of life are detrimental to cancer patients (Stanton, 2012; Gillanders et al., 2015; Zimmermann & Rodin, 2004), perhaps given the potential for avoidance of illness-related stimuli to augment exponentially, thereby inducing a state of suffering through experiential avoidance.

Aside from theoretical differences between TMT and ACT as to its aetiology, death anxiety remains prevalent amongst cancer patients, and so it is perhaps more clinically relevant to explore ways to alleviate the distress with which it is associated. Gonen et al. (2012) concluded that death anxiety was most closely related to anxiety and depression, and occurred more frequently in cancer patients with co-morbid mental health problems than those without. One interpretation of this finding is that attempts to minimise or avoid different emotional experiences have failed in their entirety, resulting in the presentation of distress across a number of different presenting problems. Although TMT would suggest this requires an increase in avoidant defences, if anxiety and distress are in full awareness, then these defences have failed to work thus far, and are proving maladaptive in the context of disease (Kastenbaum, 2000). TMT's claims that bolstering defences leads to functioning with minimal anxiety in response to threats (Greenberg et al., 1992) is therefore not supported or justified for this population, given that cancer patients experience high death anxiety, alongside the use of avoidant response styles.

Although the prospect of mortality is likely to evoke emotions, from an ACT perspective the resulting death anxiety would not be due to an underlying innate construct, as suggested by Becker (1973). It would be the result of cancer becoming related to death and to fear through an individual's relational learning history, perhaps influenced by Western culture (Charmaz, 1980). A further point of difference is whether or not death anxiety augments due to failing defences against an underlying and intolerable construct, or because of the increasing and problematic attempts to avoid these internal experiences. Within an ACT model, the inner experiences themselves are therefore painful, but not pathological. ACT would consequently encourage a stance of acceptance and the use of approach, rather than avoidant, response styles, to change the way cancer patients relate to their death-related inner experiences. This premise consequently presents a rationale for researching whether acceptance is predictive of better outcomes in a death-anxious cancer population, or whether acceptance is likely to be harmful, perhaps because death anxiety truly is an unbearable and problematic emotion in itself.

1.3. Response Styles and Coping

1.3.1. Definition and Measurement of Coping

Coping is an effortful, adaptive, behavioural or cognitive attempt to manage stressful demands (Lazarus & Folkman, 1984), where stress is seen to emerge from the appraisal of a situation as exceeding resources, or threatening wellbeing. Whether or not coping is helpful or successful may depend on its function, and thus coping needs to be understood from a functional contextualist perspective (Hulbert-Williams, Storey & Wilson, 2015). This notion is reflected in the author's reluctance to state definitive, aggregate scales for coping items, or to specify which styles are adaptive or maladaptive, for scores on the Brief COPE (Carver, 1997).

Coping styles are an established predictor of distress and quality of life (Carver et al., 1993; Stanton et al., 2000), and, as a family of behaviours coping styles have been grouped and clustered in myriad ways over preceding decades, including problem-focused and emotion-focused coping (Folkman & Lazarus,

1985); passive and active coping; and avoidance-oriented and approach-oriented coping (e.g. Roth & Cohen, 1986). Optimism and pessimism are also related to faring better and worse in terms of distress, though the mechanism by which this occurs appears to be the mediational effect of approach and avoidant coping, respectively (Carver et al., 1993). Given the lack of consensus across the expansive coping literature, empirical and conceptual problems with defining coping have been identified (McCracken & Eccleston, 2003), potentially impacting on the reliability of individual and sub-grouped coping styles within different studies. For example, it has been found that both problem- and emotion-focused coping styles may be subsumed into, and co-occur within, the broader categories of avoidance and approach-oriented coping. As such, the problem- or emotion-focused categories initially proposed by Folkman and Lazarus (1985) may have been too dichotomous, lacking in both ecological and construct validity, and also low in reliability, as defining factors within these categories has been unstable and largely inconclusive over time (Litman, 2006).

1.3.2. Terminology in the Present Study

The journal article that this extended paper expands upon used the term response styles, rather than coping styles throughout. This was an attempt to distinguish acceptance in an ACT context from the version of acceptance commonly measured in coping styles literature, by the COPE and Brief COPE measures (Carver, 1989; Carver, 1997). In reality the terms 'coping styles' and 'response styles' are interchangeable, both referring to responses to contextual demands, stressors, or cues, but only one term was used in the journal article, in order to ensure clarity and consistency. However, the literature on coping and the Brief COPE measure remains relevant to this research, and was drawn upon in the conception of the study.

For the purposes of this research, coping is taken to mean voluntary responses, rather than those which are involuntary and automatic. Voluntary responses pertain to cognitive or behavioural reactions which occur as a result of what Lazarus (1966) termed secondary appraisal, i.e. making the choice of how to respond, following the appraisal of a stressor. Furthermore, as similarly stated by Carver and Connor-Smith (2010), responses in the context of this research

are processes consciously accessible, rather than the unconscious drives commonly alluded to in psychodynamic theories of behaviour.

1.3.3. Approach and Avoidant Coping

Approach coping is aimed at tackling perceived threats and the associated emotions which follow them, whereas avoidance coping is aimed at escaping these factors (Skinner, Edge, Altman, & Sherwood, 2003). Different avoidant coping styles, for example denial, behavioural disengagement, or distraction, may therefore be cognitive and behavioural forms of experiential avoidance, which is the opposite process to acceptance. This comparison has been supported by factor analyses showing experiential avoidance and avoidant coping styles to load on the same factor (Karekla & Panayiotou, 2011). This study adopted the broader terms of approach and avoidance coping as a framework for considering acceptance and the Brief COPE styles included in the final analyses, as this distinction is thought to be of the 'greatest importance' in influencing psychological outcomes over time (Carver & Connor-Smith, 2010). It also helps to structure the research question of whether acceptance is a more beneficial, 'approach' response style than other 'avoidant' forms of coping, for a cancer population, and has been used elsewhere in psycho-oncology literature as a high-order categorisation of coping styles (e.g. Stanton, Dannoff-burg, & Huggins, 2002). Within the dimension of avoidant coping, two further sub-categories of active and avoidant emotional coping have been adopted by some researchers (Gillanders, Sinclair, MacLean, & Jardine, 2015; Schnider, Elhai, & Gray, 2007).

Although it is likely that individuals use more than one style of coping when they are stressed (Tennen, Affleck, & Armeli, 2000), individuals' choices of coping styles are thought to be relatively persistent over time (Carver, Scheier, & Weintraub, 1989), characterising their interactions with the environment (Moos & Holahan, 2003). Furthermore, the use of particular coping styles, such as denial, may increase when a situation is perceived to be uncontrollable, and when it matters more to individuals (Carver et al., 1989), so we might reasonably expect a person who habitually avoids to become more avoidant when faced with a threatening situation, such as cancer. Coping styles are

thought to determine the impact of adverse events on emotional functioning, in both the short and long term (Skinner et al., 2003), with approach-oriented coping styles linked to better distress and quality of life outcomes than avoidant coping styles (Gillanders et al., 2015). In the short-term, avoidant coping strategies, e.g. distraction, might be helpful in reducing anxieties, and thereby become negatively reinforced. However, evidence suggests that over longer periods of time, such avoidance can have a detrimental impact on engagement in valued activities and psychological wellbeing (Hayes & Pankey, 2003). Accordingly, avoiding cancer-related cognitions increases the risk of psychological distress in cancer patients (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005). Furthermore, avoidance in an illness context can prevent engagement with behaviours as important as treatment compliance, or seeking medical assistance (Šoštarič & Šprah, 2004).

Although overall there has been little conceptual consistency regarding individual coping styles in the literature, with definitions varying between authors, denial is broadly taken to mean a “disavowal of reality,” (Lazarus & Folkman, 1984, p. 136), which is utilised in an attempt to mitigate or avoid internal responses. In this study, denial pertains to the form of denial as measured by the Brief COPE (Carver, 1997); namely, a refusal to acknowledge a stressful situation. Perhaps more importantly, despite the variations in terminology, there is a consensus in the literature that denial is an avoidant strategy, whether applied consciously or unconsciously. In the context of this research, denial is a conscious construct, rather than the unconscious form of denial traditionally alluded to in psychoanalytic literature.

There is some theoretical disagreement surrounding whether avoidant strategies such as denial are helpful, and to an extent this is dependent on the theoretical approach taken. In the context of cancer, Terror Management theorists might advocate the use of increased denial and other avoidance strategies, to guard against the risk of becoming overwhelmed by death-related anxiety. Theoretically, this may be more aligned to unconscious denial, but it could also be argued that for many cancer patients, anxieties about their illness are very much in conscious awareness. Death anxiety becoming conscious may

be as a result of previous, routine avoidance strategies no longer functioning effectively, in the face of changing health status, the illness context, and the proximal threat of disease. Continued reliance on denial in this case would serve the function of avoidance, possibly perpetuating and even increasing the feared, aversive experience of cancer-related anxieties. Although no singular coping style is entirely good or bad in itself (Carver, 1989), an ACT model of psychopathology would suggest that coping styles become unhelpful when they are avoidant and excessively relied upon, such that preoccupation with avoidance comes to restrict valued behaviour, and prohibit adaptation to changing environments. Furthermore, a considerable amount of literature supports the notion that thought suppression, as might occur in the denial of illness or of death-related thoughts (Pyszczynski, Greenberg, & Solomon, 1986), is an ineffective strategy which can inadvertently result in thoughts returning more frequently, and with increased emotional salience; thereby perpetuating distress (Masedo & Esteve, 2007; Abramowitz, Tolin, & Street, 2001).

1.3.4. The Role of Appraisals in Responses

Much of the existing coping literature emerged from theories of stress, due to the common role of appraisal implicated in both emotional responses and response styles. In health populations, a causal relationship has been postulated between illness representations (appraisals) and the selected response style(s) which are then employed (Leventhal, Meyer, & Nerenz, 1980). These illness appraisals may be influenced by perceived symptoms, causes, consequences, control, and duration (Broadbent et al., 2015; Meyer, Leventhal & Gutmann, 1985). Research has also shown that the stronger the perceived illness threat, the worse functioning, distress, quality of life, and the more avoidant the response styles that are utilised (Hagger & Orbell, 2010). Although illness appraisals may be central in eliciting emotional and cognitive reactions, even more so than objective disease characteristics (Rand et al., 2012), the psychological and disease outcomes associated with these appraisals may occur as a result of response styles, or what Lazarus (1966) termed secondary appraisals. Therefore, initial unpleasant thoughts and feelings elicited by illness appraisals may be compounded by a range of avoidant responses, adversely affecting psychological outcomes. Furthermore, ACT researchers would

suggest that avoidant response styles may be used as an attempt to experientially avoid difficult internal thoughts and feelings brought about by the threatening illness appraisals (Harris, 2006). Problematic relationships to our inner experiences may therefore influence the response styles we choose, as we attempt to manage our internal responses to perceived threats, such as illness. ACT proposes acceptance of these inner experiences as the counter to experientially avoidant response styles, which have negative consequences for many healthcare populations, such as chronic pain (McCracken, 1998) and end-of-life cancer (Nipp et al., 2016).

The proposed ACT mechanism by which clinical suffering occurs, i.e. through experiential avoidance, could help to explain many of the significant correlational findings that have been reported between threatening illness appraisals and poor outcomes (e.g. Galli et al., 2010), whereby response styles mediate the relationship between appraisal and outcome. Of note, a more accepting response style may in time also affect primary appraisal and the physiological response to stressors (Hoffman, Heering, Sawyer, & Asnaani, 2009), or perhaps the reporting of how threatening an illness is perceived to be (Liverant, Brown, Barlow, & Roemer, 2008). This is not however the focus of this research nor of ACT interventions, which construe acceptance as a response-focused, rather than antecedent-focused strategy (Wolgast, Lundh, & Viborg, 2008). Whether or not initial appraisals are changed, outcomes can still be affected by shifting relationships to the inner experiences evoked by these appraisals, and by changing the problematic and avoidant attempts at emotional monitoring and control that can determine psychological outcomes and wellbeing (Kulpa, Ziętałewicz, Kosowicz, Stypuła-Ciuba, & Ziółkowska, 2016).

1.4. The Role of Verbal Language in Experiential Avoidance

Verbal language enables us to relate stimuli to each other arbitrarily and in different ways. This can result in stimuli functions changing, so that they acquire new properties, even without direct experience. These properties, transferred to new stimuli through relational learning, can then elicit responses, and the way in which we then respond to stimuli changes accordingly (Blackledge, 2007;

Hayes et al., 2011). Verbal language can therefore become increasingly problematic, as the networks of relations between verbal events and their transferred properties expand exponentially. We can consequently experience emotional responses, even in the absence of overt environmental cues, just through verbally recalling events. If we then attempt to avoid these painful experiences, greater numbers of symbolic representations may become related to them, and thus avoidance has to augment in order to try to avoid a growing number of pain-eliciting stimuli. In attempting to avoid pain, we therefore inadvertently limit our valued and meaningful action, and it is this avoidance which is key to ACT's models of psychopathology and intervention (see extended paper 1.8).

1.5. Background to Acceptance and Commitment Therapy (ACT)

An overview of ACT will provide some background to the focal aspect of this research: acceptance. This clarity is particularly important given that the word 'acceptance' can mean a range of things depending on context, and is frequently used in social parlance to allude to a state of passiveness, resignation, or 'giving up' (see extended paper 1.7.1). Here, acceptance pertains to the opposite of this withdrawal or avoidance, and is a response to internal experiences which involves relinquishing unhelpful attempts to change or evaluate them.

In ACT, the phrase 'psychological pain' is used to describe the everyday psychological distress that we as humans encounter throughout life. ACT makes a distinction between psychological pain, and suffering; the latter being an experience which occurs due to our very attempts to avoid and control psychological pain and its emotional consequences. According to Hayes and Smith (2005), suffering is the result of "a rigged game," by which the authors imply that our efforts to save ourselves from pain are actually self-defeating, due to the role of language in our mental and emotional lives (see extended paper 1.4). ACT states that human language has given us the ability to predict and solve problems, which is extremely advantageous in the outside world, but can lead to suffering when these problem-solving abilities are then applied to our innermost thoughts, feelings, memories, and sensations. Attempts to ignore

or rid ourselves of these emotional experiences, or 'problems,' can become so restrictive that we are prevented from acting in line with our values. Furthermore, as any situation can become related to the pain we are attempting to avoid through relational framing, this pain is inadvertently evoked in more and more situations. Cognitive avoidance techniques thus take up time and energy which could otherwise be spent on positive and effective action. It is therefore not the experiences themselves which become the problem, but our increasing attempts to avoid and control them. Accordingly, symptom reduction is not the primary target of ACT, as people are encouraged to accept, rather than resist, psychological pain; though it may be a secondary by-product of changing how we respond to our inner experiences.

ACT consequently seeks to reduce the impact of emotional experiences, rather than to reduce the experiences themselves, by shifting our relationship to the perceived problems. This shift is achieved through developing acceptance: the direct opposite of emotional control (see extended paper 1.7 – 1.73). Through encouraging the acceptance of difficult internal experiences, ACT renounces the *assumption of healthy normality*, i.e. the suggestion that psychological health equates to an absence of psychological pain (Hayes, Strosahl & Wilson, 2011). Furthermore, ACT suggests that the pervasiveness of the belief that psychological pain is an abnormal symptom enhances people's strivings to avoid pain symptoms, and through this avoidance they paradoxically harm themselves in the process. It is therefore the cognitive, problem-solving processes which make us human that are also the mechanisms by which we suffer, as a result of our attempts to problem-solve our way out of psychological and emotional pain.

Rather than assuming a healthy mind is pain-free, and that pain emerges due to faulty intrapsychic processes, ACT instead places great emphasis on understanding the function of internal behaviours in a given context, and how they are related to problematic actions, rather than trying to modify internal experiences directly. ACT does not attempt to alter cognitions on several counts: first, associative learning has already taken place, and cannot be unlearned; secondly, in challenging the thoughts they can become more salient;

and finally, experiential avoidance may continue unless the context is changed (Hayes, Levin, Plumb-Villardaga, Villatte, & Pistorello, 2013). ACT and other so-called 'third wave' contextual behavioural therapies, such as Dialectical Behavior Therapy (Linehan, 1993), and Mindfulness-Based Cognitive Therapy (Segal, Williams, & Teasdale, 2002), therefore represent a departure away from the underlying tenets of the cognitive aspect of cognitive behavioural therapy (CBT), through their focus on the roles of acceptance, mindfulness, attention, and the importance of the function (rather than content) of cognitions (Hayes, 2004). As ACT does not target symptomology directly, viewing the struggle as the problem rather than the 'symptoms' themselves, it focuses instead on enriching and expanding a person's life around their perceived problems. ACT can consequently be considered a model of wellbeing and health promotion, rather than of psychopathology.

1.6 ACT Core Processes

Whereas psychological flexibility is considered to be fundamental to psychological health (beyond the absence of psychological symptoms or 'disorder'), its opposite, psychological inflexibility, occurs when behavioural repertoires become rigid and insensitive to context, limiting personal and social functioning. ACT therefore aims to increase psychological flexibility, through the six, interconnected core processes demonstrated in the hexaflex below (Figure 4). Here, both the presence and absence of psychological skills are shown, with the model demonstrating both psychological wellbeing and psychopathology. The six-process model informs ACT interventions, with the goal of creating a rich and meaningful life through present-moment contact and valued action; whilst being aware and accepting of painful experiences (Harris, 2006; Hayes et al., 2006). Five ACT process will be outlined briefly, but as acceptance is most relevant to this research, and also underpins many other ACT processes, it will be explored separately in section 1.7.

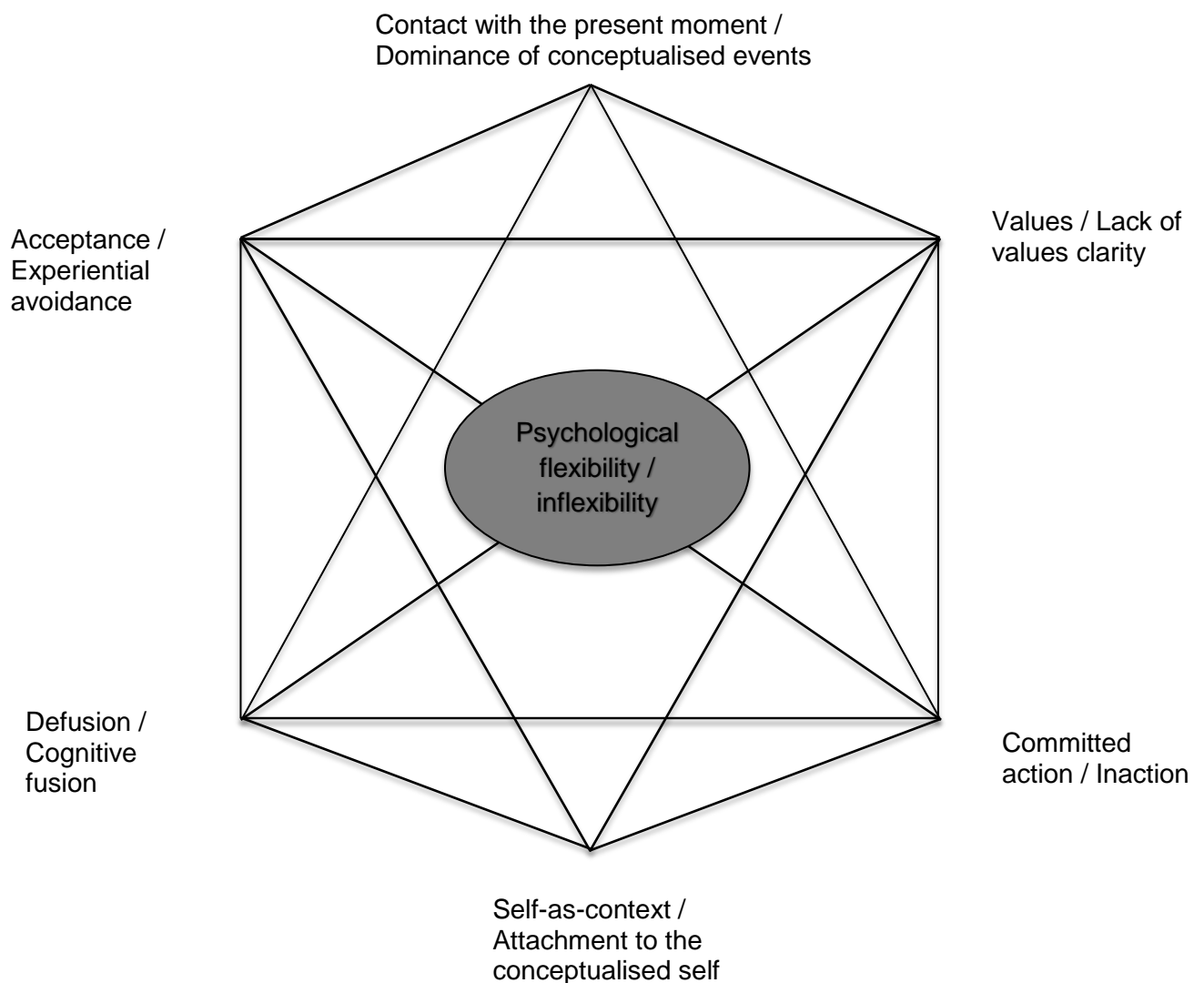


Figure 4: The ACT hexaflex of psychological wellbeing and psychopathology (adapted from Hayes et al., 2006).

1.6.1 Contact with the Present Moment

Each of the ACT core processes is linked to the present-moment, without awareness of which clients would not benefit from ACT interventions (Hayes, Strosahl, & Wilson, 2011). Contact with the present moment is bringing awareness to what is being experienced in the here-and-now, as it shifts and occurs, i.e. developing an observing self. Through this increased access to direct experience, activities can be focused on and fully engaged with. Such contact has previously been lost, due to preoccupation with avoidance strategies. Language is used to describe and label events as they occur moment-to-moment, noticing them in the present rather than considering the past or future with judgement and prediction. This process enhances our ability

to be flexible in our interactions with the environment, where they were previously limited by rigid attentional control.

Present moment awareness also requires an accepting stance, in order that there is a receptiveness to focus on and engage with whatever experiences are occurring. Furthermore, present moment awareness, acceptance, and defusion are all processes used in and enhanced by mindfulness: an awareness developed through “paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” (Kabat Zinn, 2003; see extended paper 1.6.2). With the acceptance of aversive internal experiences, these attentional processes allow a person to pursue valued activities, rather than continuing to engage in problematic avoidance behaviours.

1.6.2 Self-As-Context

Self-as-context, or the ‘observing self,’ is the ability to adopt a perspective-taking position, and so to separate experiences from a sense of self. There is a distinction between a) thoughts and feelings that arise in any given context, and b) the person observing those thoughts and feelings. Thus, a person does not need to be threatened or defined by the content of thoughts and feelings when they occur. ACT uses metaphors, mindfulness, and experiential exercises to develop ‘self-as-context’, thus undermining ‘self-as-content,’ and enhancing psychological flexibility.

1.6.3 Defusion

Cognitive defusion is the process by which the undesirable function of thoughts and private events is altered, shifting a person’s relationship to those experiences, rather than attempting to alter the form or content of the events themselves. This is achieved by creating contexts within which the unpleasant functions become lessened, and the dominance of relational frames over behaviour become weakened. Cognitive fusion is the state where people take their thoughts literally, leading their behaviour to become excessively ‘rule governed.’

In defusion, thoughts, memories, and images are mindfully observed and perceived as those very occurrences, rather than as truths or rules to be obeyed. An example of this might be learning to separate the thought “I am a bad person and do not deserve to be happy” from noticing “I am having the thought that I am a bad person who does not deserve to be happy.” Techniques which encourage defusion include repeating words until they become only sounds, thanking the mind for a thought, and acting in a way that contradicts the thought. By reducing the literal attributes of thoughts, people become able to respond to what the thought or image represents (some words strung together in a sentence; a picture in the mind), rather than to the content as bona fide truth. Word repetition has been shown to decrease the believability of self-attacking thoughts, as well as the distress they once evoked (Masuda, Hayes, Sackett, & Twohig, 2004).

1.6.4 Values

Goals in ACT are informed by values, i.e. what truly matters to a person in terms of their life and what is meaningful to them. Values are seen as chosen life directions, described by Hayes and Smith (2005) as being qualities joining a string of unfolding actions together into a meaningful path. Values can never be entities that are owned or achieved, but rather guide actions and are something that is worked towards in an ongoing manner. Values are therefore overarching directions, whereas goals are temporary, concrete, measurable entities which act as milestones and can be used to monitor progress in living a valued life. ACT interventions are evaluated by the extent to which a person is reaching goals and acting in line with their chosen values, and whether they are successfully changing their behaviour in order to do so.

Although they have benefits in themselves, mindfulness and acceptance processes in ACT are not standalone exercises. They are employed with the aim of helping a person to live a values-consistent life. ACT places great emphasis on striving towards values (which are often defined on domains such as relationship; career; friendship; leisure; health), which practitioners can use in motivating people to experience the pain and aversive experiences they have

previously attempted to avoid, in the service of working towards a more meaningful life.

1.6.5 Committed Action

Committed action is behaviour undertaken to achieve goals and work towards verbally-stated personal values, i.e. the translation of values into behaviours. Behaviour change in ACT is subject to many traditional behavioural techniques which increase or decrease the frequency of certain behaviours, such as positive reinforcement and exposure (Hayes et al., 2006). However, ACT processes of acceptance and awareness can add an advantage in addressing potential barriers to change, for example when values-consistent behaviour will involve making contact with feared experiences, or when previous attempts to do so have been unsuccessful. Furthermore, as each of the ACT processes are interdependent, it is unlikely that valued, committed action would be taken successfully until a person gains the psychological flexibility required to become more sensitive to reinforcement contingencies, as this ability is compromised when under rigid, rule-governed control (Hayes et al., 2011). The successful enactment of, and choosing of, values is therefore contingent on each of the other ACT processes, which in turn are best understood and undertaken in the context and service of valued action (as represented by Figure 4).

1.7 Acceptance

1.7.1 Acceptance in Different Forms

Acceptance has been described as ‘making room’ for the unpleasant feelings, thoughts, and urges we experience, allowing them to occur without judging them, avoiding them, or being overly concerned by them (Harris, 2006). Acceptance in ACT is therefore not resignation or self-defeat, but an active, “vital embrace of the moment” (Hayes, 2005, p.7), akin to an attitude of willingness. It involves a non-judgmental stance towards feelings, thoughts, and the self, so that these experiences can be fully embraced, freeing us from struggle and instead allowing us to engage in activities of valued and meaningful living. The opposite of acceptance is experiential avoidance, which is any attempt to control, avoid, or directly alter the inner experiences of thoughts, feelings, memories, or physical sensations, and when relied upon, is

implicated in the ACT model of psychopathology (Hayes et al., 2011). Even though acceptance of inner experiences may fluctuate over time (Flaxman, Blackledge, & Bond, 2010), which is understandable given the long history of dominant cognitive fusion processes, any overall reduction in experiential avoidance and more engagement with valued activities still represents positive change. Furthermore, there may be times when to experientially avoid is functional, but as with any avoidant response, long-term and indiscriminate reliance on avoidance has been associated with many adverse outcomes, including anxiety and chronic pain (Kashdan, Barrios, Forsyth, & Steger, 2006; Ruiz-Parraga & Lopes-Martinez, 2015).

From within an ACT framework, acceptance therefore has a very specific definition, which may differ greatly to its use in common parlance, or in other theoretical contexts. In common usage within an illness context, acceptance may be talked about in terms of someone coming to terms with a terminal prognosis, and is positioned as the opposite to a state of denial (Hulbert-Williams, Storey, & Wilson, 2015). For example, in well-known models of grief, such as the grief cycle by Kübler-Ross (1969), acceptance is the final stage in a theoretical grieving process entered by those who are dying themselves, or who have been bereaved; though the processes by which one moves through different stages are not clearly delineated in the literature. Although the stages have been somewhat decontextualized in modern applications of the model, and were never intended to be interpreted as occurring in a fixed order, acceptance in the original context of the model does still refer to a state where a person no longer experiences difficult emotions, such as anger (Guex, 1994). This idea is theoretically inconsistent with the view of Hayes (1994), who posits that the occurrence of emotional experiences is beyond our control, and key to being human. The notion that the ideal state of acceptance is reached when we no longer experience difficult emotions also implies that the emotions themselves, rather than experiential avoidance, are problematic, and somehow obstruct people from reaching an 'ideal' state of emotional stability. It has been noted, however, that higher levels of acceptance (as intended in the ACT context) may over time lead to fewer 'negative' emotions (Rothbaum, 1982), suggesting a pattern of circularity, whereby acceptance may come over time to

affect appraisals of distress, as well as being a response applied following initial appraisal.

By the logic of the grief cycle, acceptance is considered an outcome and an end stage in itself, which occurs once the emotional stages preceding it, e.g. anger and depression, have been passed through. It is therefore implied that acceptance is a desirable and final destination, rather than an ongoing, active embrace of emotions and inner experiences. Contrastingly, ACT suggests that acceptance itself is a tool for living alongside these feelings, which could be actively employed at any stage in the cycle of grief, rather than only occurring as an end stage or outcome following the feelings somehow being resolved. Thus, acceptance in an ACT sense is both a tool for achieving change, but also acts as a mechanism of change in itself (Hayes & Pankey, 2003). Acceptance, when conceptualised as an end stage where emotions are escaped, as in the grief cycle, may therefore be more akin to a state of passive resignation or disengagement than an active embrace of emotion, and is thus unlikely to facilitate valued living due to the impact of experiential avoidance upon psychological inflexibility. Although ACT would commend relinquishing a fight against inner experiences, this is through conscious choice and is distinct from a state of resignation (Hayes & Smith, 2005), in that it still requires and encourages active engagement with inner experiences. Thus, 'giving up' or relinquishing a fight in ACT is separate and distinct from helplessness or resigning oneself to emotional distress, with a key difference between the two types of acceptance determined by whether or not it allows a person to continue engaging in valued behaviours, thus maintaining or improving quality of life.

A further facet of the acceptance stage in Kübler-Ross' (1969) work is of a coming to terms with reality, notably accepting the fact that ourselves, or those who have died, are not returning. Acceptance here seems to refer to accepting a cognitive reality, rather than accepting inner experiences. Whether or not these two realities (the reality of a situation and the reality of present moment emotions) are separable is a point of contention, as paying moment-to-moment attention to our inner lives is arguably our reality at that given time. Experiencing loss is undoubtedly very painful, but in suggesting we can only

cope with reality when we have reached a state of acceptance, acceptance is again positioned as an end state, devoid of emotions or emotionally-evocative thoughts. Conversely, within ACT, acceptance is a chosen embrace of these inner experiences, which may or may not continue to occur, but which will not obstruct continued valued action and engagement unless met with experiential avoidance.

1.7.2. Acceptance and Mindfulness

Acceptance is cultivated and practiced through mindfulness, which brings moment-to-moment experiences into attention, combining the two ACT processes of acceptance and present-moment awareness. Acceptance is also required in the other ACT processes of defusion, contact with the present moment, and self-as-context (Hayes et al., 2006). Values and committed action may be the behavioural components of ACT, but such actions take place whilst experiencing internal events, and there must therefore be an awareness and willingness to allow these to occur. Mindfulness is therefore a strategy by which acceptance and awareness are practiced, in order to engage with one's valued behaviours. In this sense acceptance helps to facilitate values-based action, through a willingness to experience increased contact with the external world (Hayes et al., 2006). Furthermore, cultivating present-moment awareness and attention without a willing acceptance of inner experiences may serve to increase experiential avoidance, and therefore acceptance is key to these activities. Some emerging evidence suggests that mindful awareness or increased insight without acceptance, combined with the presence of negative illness beliefs, may increase depression, suicidality, or demoralisation in clinical-level mental health problems (e.g. Osatuke et al., 2008).

Almost mirroring ACT's commitment to a contextual approach, Kabat-Zinn (2003) cautions against the temptation to manualise and apply mindfulness to clinical problems, without understanding the context in which it belongs. For example, in its increasingly popular presence in society, decontextualised mindfulness may become touted a curative intervention or relaxation strategy, with the advertised purpose of addressing, or even fixing, 'abnormal' distress. Hayes et al., (1994) refer to this resistance and renouncing of distress as the

assumption of healthy normality. However, a true mindful approach would require a complete departure from the medicalised, curative perspective so pervasive in modern society, and instead invoking a willing openness to accept both good and bad experiences, rather than trying to forcibly eliminate unpleasant ones, or search out a 'cure' for normal, human psychological pain.

1.7.3. Acceptance vs. Reappraisal

A distinction has been made between the roles of antecedent-focused and response-focused emotional regulation strategies and interventions (Wolgast, Lundh, & Viborg, 2008). Within this overarching model of emotion generation (Gross, 1998), emotions (which have both cognitive and physiological components) can be regulated at either the level of initial appraisal, prior to the emotion fully occurring, or during the response, after the appraisal and emotion has occurred. Common psychological interventions using antecedent-focused techniques include cognitive therapy (e.g. Beck, 1979), which attempts to shift appraisals in order to alter the feelings and behaviours which they elicit. A critique of this approach from proponents of an acceptance approach would be that cognitive interventions uphold the notion of asserting control over cognitions, by replacing them with more accurate or balanced appraisals as a mechanism of change. Attempts to assert control over inner experience are a purported mechanism of psychopathology, whereby such attempts are in effect avoidance, and more problematic than the experiences themselves (Hayes, 2004). In order to alter their form, 'maladaptive' cognitions must first be suppressed, which only increases their frequency and salience (Hayes, 2004).

However, it could also be argued that acceptance is in itself a form of reappraisal, as accepted inner experiences may then be re-evaluated and reappraised as less intolerable in the future. Altering cognitions in this way is not the direct focus of ACT interventions, which instead aim for the opposite: to foster acceptance without controlling or suppressing any internal experiences (Hofmann & Asmundson, 2008), thereby changing the context, and not the content of internal events. Nevertheless, although much of the ACT literature dismisses reappraisal interventions for being experientially avoidant, there is some evidence to support reappraisals as equally, or in some cases more,

effective at diminishing distress as acceptance-based interventions (Hoffman, Heering, Sawyer, & Asnaani, 2008; Arch et al., 2012); though randomly assigning participants to experimental response style conditions may not account for the time it takes to develop acceptance skills.

A point of convergence is that both ACT and cognitive reappraisal interventions are more effective for psychological outcomes than emotional suppression techniques. This may cast some doubt on ACT's claim that reappraisal is likely to have the same negative effect as thought suppression, i.e. an increase in unwanted thoughts; though there is some debate as to whether the mechanisms of reappraisal are clearly understood (Herbert & Forman, 2013). Regardless of whether secondary reappraisal plays some role in ACT interventions, there is evidence to support both forms of intervention in reducing distress (Wolgast et al., 2011). Substantial evidence for the superiority of one approach over the other has yet to be demonstrated, nor is it perhaps strictly necessary if both are effective and have clinical utility (Helbig-Lang, Rusch, Rief, & Lincoln, 2015). Although they differ in philosophy and proposed mechanisms of change, given that both interventions acknowledge the harmful role of avoidance in the formation and maintenance of psychological distress, there is support for the idea that ACT and cognitive approaches could therefore be used in conjunction with one another (Ciarrochi & Bailey, 2008; Gillanders, Ferreira, Bose, & Esrich, 2013), as has been successful in mindfulness-based cognitive therapy (Kuyken et al., 2010).

1.8 ACT Models of Psychopathology and Intervention

When attempts to avoid aversive internal events dominate, our ability to respond flexibly to the demands of changing contexts is compromised (Törneke, Luciano, & Valdivia Salas, 2008), so that we do not engage in behaviour that contradicts the verbalised view of ourselves. We can inadvertently live more in our verbally-remembered past and verbally-imagined future than we do in the present, thereby becoming controlled by our internal dialogues (Ciarrochi, Bilich, & Godsell, 2010). These dialogues are automatically reinforced, e.g. when we believe we have solved a problem, and as a result we continue to behave in ways that are in line with our verbal theories. The dominance of these

verbal behaviours, coupled with a lack of awareness of this process, is said to represent a state of cognitive fusion, in which a person responds to their thoughts as though they represent reality: often with painful consequences.

When cognitive fusion occurs, a person can no longer act in line with their personal values, which would provide the benefit of being rewarding and positively reinforcing. Instead, actions become regulated by unhelpful, interrelated contexts, such as literality (whereby thoughts are taken as truth), reason-giving (whereby causes for their behaviour are constructed), or experiential control (attempts to manipulate and avoid aversive internal events) (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). The verbal contexts of cognitive fusion produce attempts to alter the form, frequency, or sensitivity of internal events, thus the focus on the rules of the inner world increases, which sees valued actions becoming fewer. Such inner attempts to control and avoid 'negative' experiences, through strategies such as thought suppression, inevitably fail; instead augmenting their frequency and strengthening the number of stimuli in the relational network. Thought suppression is ineffective due to the monitoring process that is employed to see whether the thought has re-occurred, paradoxically bringing the thought back into mind (Wegner, 1989). Furthermore, avoidance of internal events enhances their emotional salience, thereby necessitating increasingly restrictive behaviours to avoid an increasing number of stimuli in the relational network that can evoke the feared experience.

In order to undermine this fusion and promote wellbeing, ACT aims to enhance psychological flexibility, and create cognitive defusion. An alternative context is constructed whereby thoughts are seen as verbal events rather than literal 'truths'. As language itself creates problematic rule-governed rigidity, ACT employs 'non-linear language' in its interventions, through the use of metaphors, stories, exercises, and experiential tasks (Hayes, 2004).

1.9. Evidence for Psychological Interventions in Cancer

Cancer is still a relatively new area in the field of psychological intervention, with psychological input having increased over the last 15 to 20 years. Psychological needs were brought into sharper focus by the burgeoning hospice movement which began in the late 1960s, and promoted a holistic treatment approach for patients with terminal cancer. The recent application of psychology to a cancer population may be reflected in the psycho-oncology evidence base, which remains limited when compared to other populations in physical and mental health.

Psychologists working in cancer care apply a wide range of psychological interventions (Grant & Kalus, 2010), which have broadly demonstrated effectiveness in reducing distress, and specifically anxiety (Andrykowski & Manne, 2006), though conclusive evidence for the most effective approach remains lacking and inconclusive (Galway et al., 2012). Such a lack of psychological treatment superiority is not unique to a cancer population, however, and also prevails in the literature on general adult and child populations. Death is a prospect often considered by, and relevant to, cancer patients and their distress (Gonen et al., 2012), yet many traditional models of dying are phase models rather than clear treatment protocols, such as the Kübler-Ross model of grief (see extended paper 1.7.1). The need for further research into psycho-oncological interventions has therefore been highlighted (Newell, Sanson-Fisher, & Savolainen, 2002). Furthermore, despite various psychological therapies reportedly reducing distress, and improving quality of life, emotional adjustment, and even cancer prognosis (Newell et al., 2002), many such effectiveness studies have been hindered in part by methodological limitations, such as common method variance, or researcher bias (Baliouis, Rennoldson, & Snowden, 2015).

Dependent on the need of the patient and the target for treatment, e.g. needle phobia, conditioned nausea, or psychological distress, common existing interventions in psycho-oncology include CBT, behavioural activation, relaxation, family systemic therapy, counselling (Macmillan, 2015), and more traditionally, psychodynamic psychotherapy. There is a lack of methodological

rigour in terms of how these are defined or implemented, adding to the lack of recommendations available in the evidence base or even NICE guidelines for psychological intervention (NICE, 2004). Interventions may be coping- or skills-related, and delivered by healthcare workers such as nurses, or more formal psychological therapies, delivered by trained therapists and psychologists for those with clinically-significant distress. There is some evidence for the effectiveness of ACT in cancer populations (e.g. Feros, Lane, Ciarrochi, & Blackledge, 2013), though much research into this population remains observational, i.e. studying the population in terms of ACT processes and psychological outcomes. These studies are revealing more about how ACT processes function in this population, and whether increasing them is likely to help cancer patients and their psychological distress (Low et al., 2012). Given the ethical concerns surrounding research with cancer patients (Reid, 2009), having a clear rationale and direction for intervention, ACT or otherwise, is likely to be important and can be supported by evidence gathered by these observational research designs.

1.9.1. Implications for Psychological Research in Cancer

Given the breadth of the cancer population as a whole, and their differing contexts, interventions need to be realistic in terms of goals, measures, and the aims of treatment; factors which may also have influenced the non-significant findings in effectiveness studies reported in several systematic literature reviews (e.g. Lepore & Coyne, 2015; Newell et al., 2002). For example, it would not be realistic or appropriate to apply cognitive reappraisal techniques if a person's thoughts about dying are realistic representations of their situation. Here, an acceptance approach might be more appropriate, given that ACT is implicated for situations with no obvious solution. Furthermore, clinical change needs to be constructed and evaluated in a way that is context-specific; reductions in measures of distress may be small but meaningful for a person at the end of life, when eliminating negative emotionality would be an inappropriate aim for intervention (Golijani-Moghaddam, 2014). These factors may help to explain why there is not a more conclusive evidence base for a cancer population, as controlled trials and other outcome studies require a scheduled number of interventions (which may not be needed nor possible in

this population), as well as a treatment protocol, specified psychiatric diagnosis, and a specific set of outcome measures; standardised variables which may not necessarily suit the settings or the psychological needs of cancer patients. Given the patient-reported need for, and positive response to, psycho-oncological intervention (Golijani-Moghaddam, 2014), it is important for any intervention to consider and meet these contextual demands. ACT, though not experimentally supported in more than ten cancer intervention studies, has been suggested as a suitably flexible intervention, and therefore represents an area of research which warrants further investigation for cancer patients (Hulbert-Williams et al., 2015).

2. Extended methods

2.1 Study Methods

2.1.1. Inclusion Criteria

This study recruited a wide range of cancer patients in different settings and at different stages of illness. Furthermore, participants with all types and sites of cancer were eligible for inclusion, in a deliberate contrast to much cancer research, which focuses on specific populations when measuring factors which affect quality of life and distress. Varied stages and sites of cancer helped to expand upon whether the utility of response styles varied with illness context, such as whether life was in imminent danger, or whether responses had an overall impact on the wider cancer population. As death anxiety theory implies that threats to life may increase anxiety and avoidant responses, the inclusion of a range of cancer stages and also a palliative sub-group allowed us to see whether results would vary by the stage of cancer; although it was also noted that the severity of illness perceptions would not necessarily be reflective of objective threat to life.

2.1.2. Recruitment Procedures

Participants were recruited from Nottingham City Hospital, Kingsmill Hospital, John Eastwood Hospice, and from Nottinghamshire county, via the Macmillan community support service team. Participants were approached by clinical gatekeepers, who were doctors and nurses within the cancer services. Gatekeepers were initially approached by email, and were met with several times to discuss the study, before agreeing to take part by approaching potential participants and handing out questionnaire packs. Clinical gatekeepers also helped to shape the demographic and clinical questions asked on the questionnaires, and also to delineate the processes involved with participants completing and sending back questionnaires. A prompt sheet was designed in consultation with the gatekeepers (Appendix A), so that they could each provide participants with consistent information about the study, before asking them to read the participant information sheets (Appendix B) and to fill out the consent forms and questionnaires if they wished to take part (Appendices C & D). It was decided that providing participants with stamped, addressed envelopes would

both preserve the confidentiality of responses in clinical settings, and potentially reduce any impact that the risk of clinicians seeing completed questionnaires might have on participants' responses. Providing envelopes also eased the burden on clinicians' workloads, as they were not involved with collecting questionnaires in or handing them back to the researcher; time-consuming activities which could have impacted upon their clinical duties and was therefore not optimal for patient care. Recruitment of participants took place between September 2015 and February 2016.

2.1.3. Online and Paper Participation

The recruitment strategy of using both paper and online versions of the questionnaire was designed to target maximum numbers of participants, in as broad a number of contexts as possible. The online questionnaire allowed recruitment to be extended beyond hospital settings, thereby targeting participants who no longer had cancer, and whose experiences may therefore have been different.

Participants were able to participate in the study online, and were targeted via advertisements placed on social media platforms (Facebook and Twitter), and online cancer fora, such as Cancer Chat. Permissions were sought from website administrators via email before advertisements were placed on these fora. Online participants were asked to create a pseudonym, by combining the month of their birth with the first three letters of their mother's maiden name, for example '03FOR'. These pseudonyms were then used to record and track participants' data, so that their responses could be matched up if they participated in a follow-up questionnaire three months later.

Paper questionnaires were each issued with an assigned code, pertaining to the hospital or hospice where they were given out, e.g. 'NC31' = Nottingham City Hospital, participant number 31. This identifier allowed the researcher to track which gatekeepers were issuing questionnaires, and to liaise with any who were not, to see whether they were experiencing issues. The unique identifiers also allowed for questionnaire responses to be stored separately from consent forms displaying participant names and contact details, in line with data

protection procedures. However, as both paper questionnaires and consent forms were labelled with corresponding codes, this allowed a participant's data to be withdrawn if requested, by matching up their code with their named consent form. This was a precautionary process but was not required, as no participants requested the withdrawal of their data from the study.

2.1.4. Data Storage and Coding

Data were stored on an encrypted data stick, upon which was a password-protected spreadsheet. Data on the spreadsheet were identifiable only by participant codes, with the corresponding consent forms -listing names and contact details - stored in a locked filing cabinet at the University of Lincoln. The participant codes allowed for data tracking, in order to monitor when participants had first completed the battery of questionnaires, and when they should be issued with a follow-up three months later, provided they had consented to this. Follow-up participant information sheets, consent forms, and questionnaires (see Appendices E & F) were mostly issued online, via a link sent to participants in an email; with the exception of three participants who had opted to be sent a paper questionnaire by post.

Upon receipt of completed questionnaires and consent forms, the data were stored securely in a locked filing cabinet in the University of Lincoln, only accessible to the departmental administrators and research team. The data will be stored securely for five years before being destroyed, in line with the Data Protection Act (1998) and the British Psychological Society Code of Ethics and Conduct (2009). Online data was stored securely using an online survey tool called Qualtrics, where it was password-protected and inaccessible to any external party. Participant names were not required for the online arm of the study, as participants created and were tracked by their unique pseudonyms.

2.1.5. Ethics

The study was granted ethical approval by the University of Lincoln Ethics Committee, and the East Midlands Research Ethics Committee (REC reference 14/EM/1224), in January 2015 (Appendix G). Further amendments made to the

processes of recruitment and data collection received ethical approval in May 2015 (Appendix H).

Ethical considerations in this study were informed by feedback from the NHS ethics committee, meetings with clinical gatekeepers and research supervisors, and common practices in the literature. Research has suggested that cancer patients find participating in research to be beneficial, as they are able to share their experiences and contribute to future practice (Pessin et al., 2008). Evidence for this interest was shown by the 45 participants who opted to be notified of the study results once they had been analysed. However, the primary concern voiced by the NHS ethics committee was whether issuing participants with cancer-related questionnaires was likely to induce distress. Although the questionnaire battery comprised standardised measures which have been issued to cancer participants in previous research, the ethics committee's concern required the inclusion of several statements throughout the questionnaire to preface the nature of the questions, and to emphasise that participants had the right to either leave out questions, or to withdraw from the study at any time. Furthermore, contact details for the research team were given in participant information sheets, alongside sources of support participants could consult if they felt distressed after completing the measures. Participants were asked to read information sheets about the study prior to signing consent forms, and filling out any questionnaires. The questionnaire was long enough to measure a range of processes and outcomes, but due consideration was given to its length, as participants may not have been feeling well. Short-form versions of two subscales were included in order to ensure participants were not over-burdened by a lengthy and very time-consuming questionnaire battery.

Clinical gatekeepers were appointed in order to mitigate the chances of vulnerable participants being approached and asked to participate in the study. It had also been agreed that participants' consultants or lead professionals would be made aware that they were taking part, but as the gatekeepers held those roles, a separate process for this notification was not necessary. A further ethical process decided upon was that prior to follow-up, the names of

consenting participants would be checked with gatekeepers. This was to check whether it was still appropriate to contact that person, given that the nature of disease means their condition may have deteriorated. In three cases, participants had died between initial participation and follow-up, and this safeguard therefore prevented any inappropriate contact being made, e.g. sending out a follow-up questionnaire, if the participants had chosen to be contacted by post.

2.2. Choice of Theoretical Categories

A thorough search of the literature was conducted via electronic databases and hand-searching reference lists, in order to choose the most appropriate measures for use in this study. Measures were chosen on three domains: cancer characteristics and appraisals (measured by clinical questions and Brief IPQ); response styles (measured by AAQ II and Brief COPE); and both distress and quality of life outcomes (measured by HADS, FACT-G, and DAS). However, in using three theoretical categories of variables, the study did not seek to establish temporality, as it was acknowledged that illness perceptions and responses can not only contribute to psychological outcomes, but may also influence each other. For example, an accepting stance towards emotions may over time lead to cognitive defusion, i.e. separation from thoughts about illness, which are then retrospectively reported as being less severe.

Hayes et al. (2006) have called for more 'micro studies', of key processes, to see whether they work in a theoretically-coherent way, and acceptance was the *a priori* response style of interest in this study. Acceptance may also account for a greater proportion of outcome than other ACT processes (Hulbert-Williams et al., 2015). Measures of alternative response styles were included alongside acceptance, as theoretically-related variables, and because the inclusion of additional behavioural measures has been called for, when studying how ACT processes relate to outcomes (Kashdan & Rottenberg, 2010). Specifically, response styles were considered in terms of being approach or avoidant responses, in line with the overarching theory of ACT's model of acceptance and avoidance as underlying mechanisms of health and psychopathology, respectively. Grouping Brief COPE styles together may also improve the

measure's scale reliability, given the high rate of interdependence between some of its items (Hankins, Foster, Hulbert-Williams, & Breckons, 2013). Brief COPE items were not defined in terms of groups however until after correlational analyses, which were carried out to see which items were correlated with outcomes. Final items grouped as 'avoidant' comprised self-distract, denial, behavioural disengagement, venting, and self-blame. Self-blame is thought to serve an avoidant function similar to inhibition or withdrawal, whilst venting constitutes the avoidance of moment-to-moment tolerance of emotions and active coping efforts (Carver, 1982). The decision to measure response styles was also drawn from the extensive literature base on the relationships between coping and outcomes in cancer patients (e.g. Carver et al., 1993; Stanton et al., 2000) (see extended paper 1.3).

Lazarus (1996) suggested the importance of knowing what is of particular and imminent concern to patients in order to study their response styles. Furthermore, illness appraisals have been strongly implicated in how people respond to cancer and other diseases (e.g. Rand et al., 2012), and may interact with response styles in determining outcomes (Carver et al., 1993). An illness appraisal measure provided a way to capture subjective initial illness status and meaning, and a cancer-related context for the questionnaire battery. It also allowed for the assessment of whether cancer was impacting upon patients, as if not the population would not necessarily have differed from any other. There are subjective processes involved with illness appraisal, and for this reason more objective measures of illness status were also included (such as cancer stage); though these were not clinically checked with patient records, and were therefore not immune to subjective processes. Further background variables which have been linked to responses and outcomes in cancer, such as age, and number of previous cancers, were also measured and included.

The selected outcomes were for measures of anxiety, distress, death anxiety, and cancer-related quality of life. These outcomes are common in cancer-related research and would thus allow for comparisons to be drawn between research and theoretical findings. Quality of life has been described as a "critical endpoint" in health-related research (Smith, Avis, & Assman, 1999, p. 447), and

is also affected by emotional outcomes, such as anxiety and depression. Anxiety and depression contribute to an overall picture of psychological distress, but may also affect worse physical outcomes (Gillanders et al., 2015). Death anxiety was measured as a theoretically-relevant concept, which is known to occur amongst cancer patients. Furthermore, TMT would suggest that death anxiety should only increase in the presence of an accepting response style; offering a theoretical counter to an ACT model of psychological health and emotional acceptance.

2.3. Measures

Permissions for the use of subscales were granted by the questionnaire authors, where required, and were purchased for the HADS.

2.3.1. Adaptation of Measures

The wording in-between the subscales in the questionnaire battery was partly instated as a result of the requirements of the NHS ethics committee (see extended paper 2.1.5), and partly served as a primer and contextual cue for the more general measures included on the questionnaire. For example, text inserted prior to the first item of the Brief COPE items asked participants to consider the items in relation to their cancer.

Some items on the Brief IPQ (item numbers 2,3,7,8) were altered, in line with recommendations from the author (Broadbent et al., 2015) and researchers investigating the validity of the Brief IPQ for cancer populations (Price et al., 2012; van Oort, Schröder, & French, 2011). Alterations to the wording of items made them first person, cancer-specific, and in some cases improved their clarity (van Oort et al., 2011). For example, an item which asked about perceived control over cancer, was replaced by perceived influence over cancer, with the authors' rationale for this change being that control was abstract and not necessarily internally-attributed. One original timeline question, which had poor psychometric properties for participants with short prognoses (Price et al., 2012), was replaced by an original item from the IPQ-Revised, from which the Brief IPQ was derived and which has well-established validity in cancer populations (Ashley et al., 2013). The replaced item still targeted

perceived life expectancy: 'How long do you think your illness will continue?' was therefore substituted for 'I expect to have this cancer for the rest of my life'.

2.3.2. Justification of Measures

Two questionnaires were included in their brief forms, to prevent over-burdening participants with cancer, and to prevent high rates of study attrition. The six standardised questionnaires chosen to make up the questionnaire battery are frequently used in research on distress and quality of life in health populations, and are therefore easily related to other findings. The exception to this is the DAS, as death anxiety is not routinely measured. However, the DAS has been used in cancer research, but far less frequently than measures of general anxiety, such as the HADS. The DAS remains the most widespread measure of death anxiety (Neimeyer, Moser, & Wittkowski, 2003), and was less lengthy to complete than other death anxiety measures available; a factor which was key given the likely physical health limitations of some participants. The Brief IPQ has good psychometric properties (Broadbent et al., 2015), in terms of its sensitivity to change and validity, and has been used in both long and short form in cancer populations. However, the internal reliability as measured using Cronbach's alpha ($\alpha=.38$) was lower for this study than in research elsewhere with cancer patients, possibly due to the changes made to scale items to improve their readability and validity for the population. As the scale attempts to assess "both emotional and cognitive representations of illness" (Broadbent et al., 2015, p.631), it was used here as a broader measure of the experience of cancer, in recognition of the complex and multi-factorial nature of illness.

Although there has been some concern as to whether the AAQ II has poor validity in measuring several ACT processes, which may conflate with distress outcomes (Wolgast, 2014), the AAQ II may be most reflective of experiential acceptance over any other ACT process and therefore has utility within this study, as well as ubiquity in its use elsewhere in the literature (Francis, Dawson, & Golijani-Moghaddam, in press). Furthermore, at the time of beginning this study, the AAQ II was the only validated measure of experiential acceptance, though a later further measure of acceptance has since been developed (Francis et al., in press).

There is a wealth of literature that studies response styles, as measured by the Brief COPE, and outcomes of quality of life and distress. However, little research has used the AAQ II alongside the Brief COPE, despite experiential avoidance potentially mediating the effects of coping styles upon distress outcomes (Fledderus, Bohlmeijer, & Pieterse, 2010). One potential reason for the lack of inclusion of the AAQ II in cancer research is that acceptance is an item listed on the Brief COPE, though as explained below there are theoretical contrasts between the two types of avoidance. This study included both the Brief COPE and AAQ II measures, in order to assess the contribution of acceptance to the outcomes well-known to be influenced by different Brief COPE styles in cancer patients.

Acceptance as measured by the Brief COPE alludes to 'accepting the fact that the stressful event has occurred and is real', i.e. a form of cognitive awareness of a situation rather than of one's innermost states. Carver (1982) stated that this accepting coping strategy allows people to actively engage with situations, and whilst acceptance on the Brief COPE differs in its definition from acceptance in ACT, both may facilitate approach rather than avoidant responses. The two items were included in bivariate correlations to see whether they were associated with each other, and related to outcomes in the same direction.

The FACT-G is cancer-specific, and therefore targets aspects of quality of life known to be affected by cancer, through items which ask about side effects of treatment, pain, and concerns about dying, for example. Although alternative measures of quality of life are frequently used with cancer patients, such as the SF-6D or EQ5D, these measures are expensive to use and are also not disease-specific. Thus, the FACT-G was considered a less global, and more specific option to capture cancer-related quality of health domains for this population; although the scores from the FACT-G can be mapped on to those of the EQ5D and the SF-6D to improve generalisability across research projects, as required (Teckle et al., 2013). Although not initially designed for patients in remission, the FACT-G is still useful and valid for historical cancer patients,

despite the fact some items such as 'I have nausea' may no longer be relevant (Yost et al., 2013).

2.4. Details of Additional Analyses

2.4.1. Bootstrapping

Bootstrapping is a technique which estimates the sampling distribution of a statistic by repeatedly taking samples from a data set, and is defined here due to its use in PROCESS; the statistical package used to run moderation analyses on the data set. Bootstrapping estimates these samples when samples are not large, or data is not normally distributed. The process works by calculating the parameters of each smaller sample borrowed from the overall data set, up to 2000 times. This creates parameter estimates, from which confidence intervals can be drawn (Field, 2013).

2.4.2. Chi-Squared Secondary Analyses

Chi-squared tests of association were carried out on the demographic details between paper and online participant groups, to see whether the groups differed significantly in their participant make up, on measures of cancer stage, age, and gender. These tests were conducted as secondary analyses (see extended paper 3.3.3 for the results). The chi-squared used Fisher's exact test to calculate the exact probability of the Chi-Squared statistic, which is implicated when groups are small, or of uneven sizes (Field, 2013). Chi-squared tests are used to assess whether there is a significant relationship between two categorical variables (online and paper questionnaires) from a single population (participants in the study).

2.4.3. Comparing Means in Secondary Analyses

One-way ANOVAs were carried out to explore whether there were significant differences in levels of acceptance between stages of cancer. Additional independent samples *t*-tests were also carried out to determine whether participant response styles and outcomes were significantly different between those who had only had cancer once (i.e. at the time of participation), and those with experience of multiple cancers. The rationale for these further demographic tests was that cancer stage and acceptance were significantly correlated in

preliminary bivariate correlations, and ANOVAs would reveal whether certain stages of cancer had significantly higher or lower levels of acceptance. The theoretical rationale for testing was that TMT (Greenberg, Pyszczynski, & Solomon, 1986) would predict avoidance (the unipolar construct to acceptance on the AAQ II) to be higher in late stage cancers, as a result of more proximal threat to life. Having previous experience of cancer may also have increased the awareness of death, which according to TMT would –and should - lead to more avoidant responses, and hypothesised improved outcomes.

3. Extended Results

3.1. Assumption Checking and Outliers

Suitability for multivariate analyses at both times one and two was established using an extensive range of assumption tests, which revealed no violations of assumptions. All data were checked for normality, linearity, and converted to z-scores, i.e. studentised residuals, in order to check for outliers and large residuals. A range of ± 3 was adopted when assessing z-scores, as commonly recommended (e.g. Field, 2013), and a limit of 5% of cases with scores over 2 was set. 15 scores in total initially fell outside this range, and were converted using a winzorising technique, whereby they were changed to the next highest score within the normal distribution. Z-scores were then checked again, to ensure this technique had been successful.

Tests following initial regressions checked for linearity, independent errors, homoscedasticity, multicollinearity, multivariate outliers, and influential cases. These tests included scatter plots, and plots of standardised residuals against standardised predicted values (zpred vs. zresid), to check for outliers, linearity, and homoscedasticity (see Figure 4 below for an example). Durbin-Watson tests revealed a lack of autocorrelation in the data, as all scores ranged between 1.48 and 2.07 (i.e. between 1 and 3). For each regression model, the Variance Inflation Factor (VIF) was calculated to be <10 , with tolerance statistics >2 ; results therefore fell within recommended range (Menard, 1995; Myers, 1990) and suggested a lack of collinearity in the data, i.e. the predictors in the model did not have a strong linear relationship. Although scatter plots for dependent variables showed approximately 16 points which seemed to differ from the main trend, potentially influential cases were assessed by calculating leverage values, Cook's, and Mahalanobis distances.

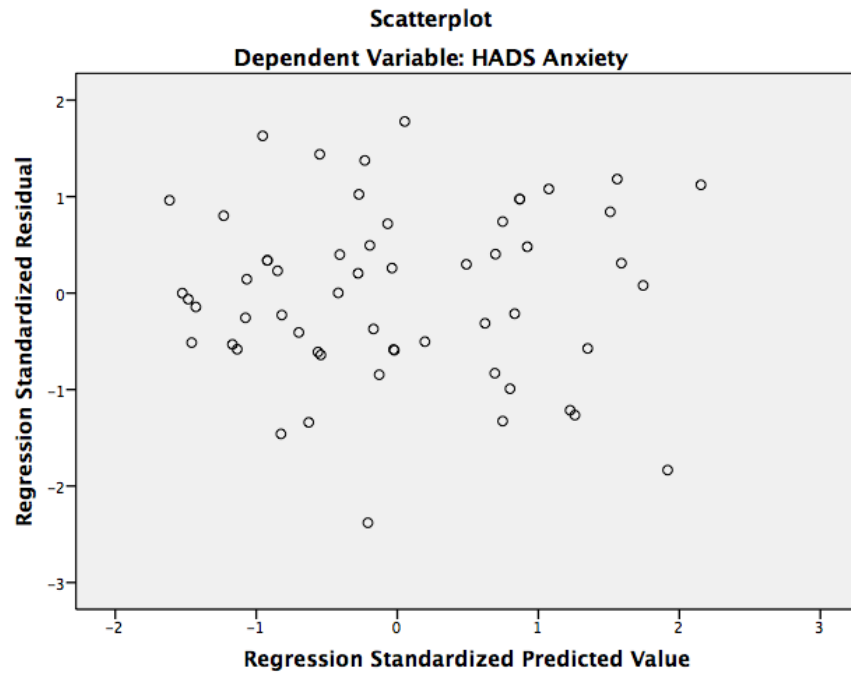


Figure 4: Regression plot of standardized residual vales against predicted residual values, with HADS anxiety as an outcome variable

Leverage values calculated in SPSS were assessed using a cut-off score calculated by the formula $(k + 1)/n$, where k was the number of predictors in the model (14), plus one ($14+1=15$), divided by the number of participants ($n=72$). The total (.22) was multiplied by three, as recommended by Stevens (2002), to give a cut-off score of .66. All leverage values were less than .66, suggesting cases did not have large influence. Similarly, all Cook's distances fell under the recommended level of 1 (Cook & Weisberg, 1982), and Mahalanobis distances fell beneath the cut-off point of 36.12. The Mahalanobis cut-off was determined by the critical value of chi-square for an alpha level of .001, with 14 degrees of freedom, as there were 14 variables entered into regression analyses in total. These tests revealed all data to be within acceptable parameters, such that no outliers were unduly influencing the models.

3.2. Power Calculations

The two power calculations were carried out using G*Power, to determine the number of participants needed to achieve a sufficient level of power (.8), on both correlational analyses and multiple regression analyses. The required

sample size would detect an R^2 increase on multiple regressions at an alpha level of .05. As the power calculation for regression was conducted *a priori*, all 14 Brief COPE variables were counted as predictors in the calculation, as it was not yet known which ones (if any) would be suppressed.

The power analyses were based on a large effect size, taken from an existing quality of life – psychological flexibility correlation coefficient ($r=.472$), reported in previous research (Hulbert-Williams et al., 2015). When converted, this correlation coefficient approached a large effect size ($f^2=.29$), based on cut-offs of .15 for a medium effect size, and .35 for a large effect size (Cohen, 1988). The total sample size required was $n=32$, for both correlations and multiple regression.

3.3 Secondary Analyses

3.3.1. Participation Statistics

Analyses of all responses revealed similar numbers of participants had taken part in paper questionnaires and online questionnaires: 52% of participants were recruited online, and 48% were recruited face-to-face, via clinical gatekeepers.

Missing values analyses revealed that the questionnaire with the most missing responses was the Brief COPE, with an average of 10 missing responses per subscale. The Brief COPE was the penultimate measure in the questionnaire battery, but the DAS followed the Brief COPE, and had fewer missing responses (5), and a larger number of completed scores. Although some participants missing out data on the Brief COPE may also have missed out the DAS, the pattern of missing values peaked at the Brief COPE and then declined. This suggests that missing out measures was not always due to attrition part-way through participation, and did not always preclude participants from completing the questionnaire to the end.

3.3.2. Prevalence of Distress in the Sample

60% of the sample reported clinically significant levels of distress, as measured by HADS scores reaching 8 or above (Zigmond et al., 1983), and 44%

experienced high death anxiety, as measured on the Death Anxiety Scale, equalling or exceeding a cut-off score of 7. A further 31% of participants obtained AAQ II scores within a range commensurate with clinically-relevant psychological distress, i.e. below 25, when the AAQ II is scored in the direction of experiential acceptance (Bond et al., 2011).

3.3.3. Further Descriptive and Clinical Characteristics

Many demographic details cited in psycho-oncology literature, e.g. religiosity and gender, were not significantly related to any demographic, response style, or outcome variables in this study. In addition to the analyses in the journal paper, some further testing was carried out to see whether outcomes varied by clinical characteristics, such as cancer stage and number of previous cancers. These tests were carried out to compare the demographics of the sample to existing research, and also to highlight potential moderating factors in psychological outcomes that could be explored further in future research.

Chi-squared tests were conducted on categorical data between the online and paper samples, to compare whether there were significant demographic details between the two groups. Fisher's exact test was used to determine significance, as some categories, e.g. age group 25-34 years, had fewer than 10 participants. The tests revealed that there were no significant differences between the online and paper populations on the domains of stage of cancer or number of cancers, but there were significant differences in gender and age, with the online sample having significantly more, and significantly younger, women than the paper sample ($p < .001$, Fisher's exact test).

Exploratory correlations with demographic and clinical details showed that age was the factor with the highest number of significant correlations. Age was significantly related to stage of cancer ($r = .34$, $p = .012$), but not to the number of cancers participants had experienced; although the average age of participants who had experienced cancer more than once was 57 years old. Levels of acceptance also correlated with age ($r = -.30$, $p = .010$), but not with number of previous cancers, or stage of cancer. Older participants reported later stage cancers, but less threatening cancer appraisals, whereas younger participants

reported more threatening cancer appraisals, higher emotional and instrumental support, and venting and planning response styles.

One-way ANOVAs revealed there were no significant differences between acceptance levels at each stage of cancer ($p > .05$), at either time one or two. Furthermore, independent samples t -tests revealed that there were no significant differences between response styles or outcomes for participants who had previous experience of cancer, and those participants who had not had cancer before ($p > .05$). The exception to this was on scores for the self-distract response style, where participants who had previously had cancer used less self-distraction ($M = 1.79$, $SE = 0.42$) than those experiencing cancer for the first time ($M = 3.13$, $SE = 0.27$). This difference, 1.35, BCa 95% CI [0.221, 2.471] was significant $t(65) = 2.39$, $p = .020$.

3.3.4. Brief COPE Response Styles and Outcomes

Acceptance as measured by the Brief COPE correlated with acceptance as measured by the AAQ II ($r = .26$, $p = .035$). This association moved towards being of medium strength, according to Cohen's (1988) convention of .3 for a moderate effect size. However, acceptance on the Brief COPE did not demonstrate any significant correlations with outcomes, and was therefore not entered into regression analyses.²³

Only avoidant Brief COPE response styles had sufficient numbers of significant associations to be retained for regression analyses, with only three brief COPE styles emerging as significant contributors to outcomes: denial and disengagement at time one, and self-distract at time two. Brief COPE styles were therefore not overwhelmingly predictive of either high or low psychological outcomes, at times one or two.

Carver (1997) warns against calculating summative or aggregate scores across the sub-scales of the Brief COPE, but states that the scale is suitable for assessing the most dominant coping styles. Therefore, of the five avoidant

²³ As previously stated, variables which did not significantly correlate with at least one response style and one outcome variable were suppressed in regression analyses.

response styles retained in the analyses, self-distraction and venting had the highest average scores across the sample, and behavioural disengagement had the lowest. Overall, avoidant coping correlated with high levels of distress in the sample, as measured by scores on HADS depression and anxiety measures.

3.4. Alternative Analyses

An alternative method of analysis which would have addressed the aims of this study would have been to use mediational, as opposed to moderation, modelling. A mediating variable *explains* the association between two other variables, whereas a moderator variable *affects* that relationship, in size or directionality. Mediation might have shown that the relationship between cancer appraisals and outcomes was contingent on acceptance, for example, perhaps implying that targeting a mediating variable, e.g. acceptance, could theoretically change a distress outcome, e.g. anxiety (MacKinnon, Fairchild, & Fritz, 2007). However, moderation is less dependent on establishing a linear sequence between variables in time, as moderators can both pre-exist or co-occur with other variables, and thus do not depend on establishing temporality between variables. In this study, cancer appraisal was used as an initial measure alongside other commonly-understood variables that might have influenced outcomes. However, despite the widespread use of mediation in psychological literature, and its appeal in explaining relationships between variables, the advantage of using moderation was that it did not rest on the assumption that the variables measured were causal, or occurred in time-ordered sequence; these are two assumptions of mediation (Gunzler, Chen, Wu, & Zhang, 2013). Such discrete categories or sequencing between variables could not be inferred in this methodology, due to questionnaires capturing variables which are measured at one moment, and the absence of an intervention to begin to separate out the order in which measured events may occur.

In order for mediation to have been an appropriate method of analysis therefore, the study design would have had to follow participants over time in order to establish whether response styles, such as acceptance, affect psychological outcomes. Tracking participants prospectively would allow for

initial baseline response styles to be measured, and then re-measured in participants within the sample who go on to be screened for, or diagnosed with cancer. The hypothesised impact of response styles upon outcomes (e.g. of distress and quality of life) could then be measured through significant changes in response styles preceding change in outcome. A clearer picture of whether response styles shift in type or frequency in response to the diagnosis of cancer could be measured, by comparing response styles at baseline, to those post-diagnoses. Furthermore, participants with cancer could also be compared to those who had not developed cancer, on the domains of response styles and outcomes. Prospective longitudinal study designs are extremely expensive and therefore relatively few in number; a brief search of the literature revealed only two that have studied distress in adults with cancer in the last decade, but such a design would allow for a more temporal chain of events to be established between the factors of initial cancer diagnosis and appraisal, response styles, and psychological outcomes.

4. Extended discussion and Critical Reflections

4.1. ACT's Philosophies of Science and of Truth

4.1.1. Functional Contextualism and Pragmatic Truth

ACT is considered to be a contextual behavioural science, and advocates for the functional analysis of behaviours in terms of their environmental context, in order to predict and influence behaviour with precision, scope, and depth (Hayes, 1993). The functions of behaviours are derived from previous contexts and learning histories, and present behaviours are seen as 'ongoing acts in context,' i.e. the past and future of an act, which also exist in the present. ACT aims to predict and influence behaviour in the service of "successful working towards one's [practical] analytic goals" (Hayes, 1993, p. 182), which must be specific and verbally stated a-priori. Functional contextualism is thereby underpinned by a pragmatic truth criterion, whereby analyses are only taken to be 'true' in terms of whether or not they lead to successful goals, i.e. the truth is what works. In this sense, there is no attempt being made to uncover *the* truth, in an objective, context-free, and generalisable sense. In fact, contextualism suggests that there can be no objective truth or reality separable from our interactions in and with the world, which are historically and contextually bound (Hayes, 2004). Actions can consequently only be understood relative to the context in which they occur, and whether they are useful, rather than 'true'. Applied to response styles, believing thoughts to be true can lead to excessively rule-governed behaviour and experiential avoidance, rather than questioning a) whether or not the thoughts have to be responded to, and b) whether or not these responses are helpful. Functional contextualism lends itself to correlational analyses, as discovering that one event is correlated with another implies that the contextual variables affecting the first event might also affect the second (Biglan & Hayes, 1996).

4.1.2. Underlying theories of measurement

There are also philosophical underpinnings to the psychometric standards of reliability and validity, to which we often hold measures and critique them in terms of scientific rigour. The notions of psychometric validity - how well a

measure assesses what it claims to - and reliability -the degree of consistency the measure allows - form part of an elemental realist epistemology (Ciarrochi et al., 2016). However, ACT is underpinned by the assumptions of contextualism, whereby a measure's context and usefulness are more important than whether or not it is reflecting a supposed objective truth about the world and a person's state of mind. Therefore, response styles must be considered in terms of whether they are useful, not just in the short-term avoidance of anxiety for example, but in terms of whether they help a person to lived a valued life that is consistent with their values and goals.

4.2. Results in the Context of Theory

4.2.1. Approach Response Styles

No approach styles measured on the Brief COPE demonstrated significant associations with acceptance or outcomes. This could be explained by ACT's understanding of experiential avoidance, which suggests that avoidance augments over time and prevents engagement with valued activities, as well as the ability to assess and change unhelpful responses. For example, engagement with approach-focused response styles, e.g. problem-solving or obtaining social support, may be obstructed by rigid and restrictive attempts to avoid inner experiences, which consequently obstruct adaptation to changing contexts (Hayes et al., 2011). Thus, it becomes difficult to utilise diametrically opposed approach and response styles simultaneously, which may also explain why acceptance and denial did not significantly contribute to any regression model simultaneously, and only did so independently of one another.

4.2.2. Acceptance as a Construct

The results indicated that acceptance was a unique explanatory and predictor variable for a range of outcomes. *t*-test results supported the notion that a person's use of coping style is relatively stable over time (Carver, Scheier, & Weintraub, 1989), which warrants consideration of whether acceptance is a state or trait type response style. The latter would imply that an accepting response style is an underlying and somewhat permanent individual characteristic. However, it may be more congruent with a functional contextualist position to consider the opposite, that response styles are likely to

be used and even augment in response to an internal or external environmental stimulus. In this case, acceptance may seem more akin to a 'state', or behaviour which is shaped and changed by context and environmental contingencies. Furthermore, according to functional contextualism, the AAQ II scores elicited in attempt to measure acceptance are also reflective of behaviour-in-context, and not of an objective underlying truth, as psychometric theory might imply.

Although the results of this study showed acceptance to be a stable construct in those participants who took part in the follow-up, it is important to note that this was not an intervention study, and no attempts to impact upon levels of acceptance were made. Although the demographic measures were not designed to capture all events that might have affected participants and their response styles between times one and two, the variables that were administered showed few shifts had occurred on individuals' demographic or clinical scores. Given that their broad experiences of illness were relatively stable therefore, with the exception of five participants whose cancer stage had changed, it is reasonable to assume that this explained why their levels of response styles also remained stable. The repetition of demographic and clinical details questions was designed to broadly capture any major shifts that might have otherwise provided some background to changed levels of responses or outcomes.

Although acceptance did not therefore shift significantly between time points one and two in this study, this could be due to a) the length of time being relatively short (three months), b) there had been no changes in the cancer-related items asked of participants, and therefore no escalation, de-escalation, or change in response styles (assuming that cancer appraisals are antecedents to responses), and c) the lack of acceptance-based intervention. The AAQ II is sensitive to change over time (Bond et al., 2011), and would be an appropriate measure to capture any shifts following any future acceptance-based interventions. The ability of acceptance levels to shift with intervention has been demonstrated elsewhere in the literature (e.g. Lillis, Hayes, Bunting, & Masuda, 2009), and given that the prevalence of experiential avoidance has been touted

as a universal problem, it seems reasonable to assume that acceptance is not a default position, but a skill that takes time and practice to master. Therefore, acceptance may act less like a trait, given that it is sensitive to change over time, when measured by the AAQ II.

4.2.3. Acceptance and the AAQ II

All of the results obtained through measurement in this study are only as valid and reliable as the psychometrics used to obtain them. Furthermore, all psychometrics measured intrapsychic rather than observed constructs, which cannot be directly measured without interpretation first taking place, inevitably influencing results to some degree.

The AAQ II has been criticised for having poor discriminant validity, and conflating distress items with process items. Therefore, results of this study and of the existing literature need to be interpreted in the knowledge that any observed relationships may be artificially inflated due to weak discriminant construct validity. The AAQ II has also been criticised for measuring both process and outcome (Chawla & Ostafin, 2007), but in this study was used as a measure of the former. Given the AAQ II's significant correlations with measures of avoidant responses on the Brief COPE, it is also reasonable to suggest that there was shared variance between measures of generalised and experiential avoidance (the unipolar opposite of experiential acceptance on the AAQ II measure) (Karekea & Panayiotou, 2011). Although the AAQ II measure has some psychometric weaknesses, it remains the most widely-used measure of experiential acceptance. Furthermore, acceptance may be what most items on the AAQ II measure, despite the authors claiming that it also measures other ACT processes and psychological flexibility (Francis et al., in press).

4.2.4. Acceptance and Cancer Appraisals

There was also a significant correlation between AAQ II and Brief IPQ scores, and the Brief IPQ at times became a non-significant predictor when AAQ II was entered into regression models. Acceptance and cognitive appraisal may thus share variance due to acceptance involving a degree of considering emotion acceptability, prior to responding to those emotions in a willing manner.

However, the results did show that acceptance added unique and significant predictive value to models, beyond that contributed by either the Brief COPE or the Brief IPQ. This may support its construct as a response, rather than appraisal variable, as although appraisals were still associated with outcomes, acceptance contributed and added variance over and above the appraisals of cancer. This may have been because it was a response style, and response styles according to ACT are the cause of suffering and distress, rather than the feelings which result from initial appraisals themselves.

The findings that acceptance, albeit with the potential limitations of the measure used, contributed unique explanatory power to regression models may therefore support ACT's theory of psychopathology rather than that of cognitive therapy. The cognitive principle (Beck, 1979) posits that faulty appraisals lead to emotional distress, whereas in ACT, the cognitive processes employed to avoid painful thoughts are the problem, rather than the thoughts themselves. A lack of correlations between disease characteristics and responses or outcomes showed that psychological distress occurred independently of physical symptoms. This suggests that illness appraisal, rather than disease characteristics, may help to influence psychological outcomes in response to cancer and its threat to life, as cancer appraisals were significantly correlated with many response styles and outcomes. The ways in which appraisals and responses may interact to influence outcomes were not elucidated by the moderation analyses in this study however, as both remained independent, significant predictors or correlates of outcomes. This may in part be because the AAQ II and Brief IPQ measures were correlated. As the appraisal - outcomes analysis was correlational, directionality could not be established, and it is therefore possible that responses influenced appraisals; a possibility further suggested by the variance shared between appraisals and responses in regression analyses. In ACT terms, the mechanism underpinning this relationship would be that cognitive defusion leads to appraisals being perceived as less severe, potentially reducing the amount of subsequent response styles employed.

Despite cancer appraisals correlating with outcomes, the results implicate response processes over these appraisals in influencing outcomes. Applying these findings to clinical practice, the potential utility of changing relationships to cognitions and inner experiences, rather than attempting to modify cognitions themselves, may be inferred from the data. Furthermore, ACT may consider the modification of thoughts and appraisals to be more likely to contribute to experiential avoidance and cognitive fusion. In contrast to this, there is evidence to support cognitive reappraisal techniques (Helbig-Lang et al., 2015), and in line with ACT's position on workability, there should not be one prescribed clinical method for working with all clients. Furthermore, although cancer appraisals had less predictive power in this study, they remained significantly correlated with avoidant response styles and poorer outcomes, in a relationship that was not moderated by acceptance. It is important to state that the results do not show that cognitive interventions would be of no benefit; only that response styles may be more significantly implicated in outcomes and perhaps interventions, as a result of contributing more to distress than illness factors themselves. A possible interactive explanation for this finding is that acceptance changes the potency of cancer appraisals, thus explaining why cancer appraisals were not predictive of outcomes, as perhaps those who were more accepting reported less threatening beliefs about their cancer.

4.3. Implications for Clinical Knowledge and Practice

In this study, death anxiety did not appear to function differently to any other measure of distress. All avoidant response styles were significantly correlated with distress, and inversely associated with quality of life. Furthermore, there was no support for the TMT theory that acceptance and death anxiety should be positively correlated, as the inverse of this was found. Death anxiety was also correlated with general anxiety and depression, and although there were no specific measures of other emotional experiences that might be associated with death, such as grief or loss, this suggests that death anxiety is related to a broader range of emotions (Hoelter 1979); all of which may become more distressing through the use of avoidant response styles. Given this generalised effect, there was no single emotional experience contra-indicated for an accepting approach. This may speak to ACT's theory that experiential

avoidance of emotions, rather than specific emotions themselves, leads to suffering. Given TMT's supposition that death anxiety is a unique and intolerable factor, the lack of evidence found to support this is an important outcome. Otherwise, advocating for increased exposure to death-related emotions in cancer patients, without first knowing whether acceptance is implicated in better or worse psychological functioning, could have had iatrogenic and unethical impact.

This study is a response to calls for further research into both ACT processes and potentially efficacious psycho-oncological interventions. Since the beginning of this study, media reports on the need for greater provision of psychological support in cancer have been numerous. Thus, the project is timely and the findings are relevant to today's healthcare population; implicating the potential role of acceptance in improved psychological distress and quality of life, and suggesting that acceptance-based interventions might therefore be appropriate to influence future functioning. As there was no difference between objective disease status or demographic variables and outcomes, distress occurred across all cancer groups; though the study was not able to show beyond this whether acceptance-based interventions were better implicated for some participants than others. The exception to this was age, whereby older participants were more accepting; a finding explained in the literature by younger cancer patients suffering greater losses, and consequently having more threatening cancer appraisals. If the emotions arising from this perceived loss are then avoided, as shown through increased use of venting and planning response styles in this age group, this would explain greater distress amongst the younger demographic.

Where traditional cognitive behavioural therapy (CBT) involves the use of techniques such as planning, positive reframing, and instrumental support, this study found no empirical support for associations between these strategies and quality of life or lower distress, raising the question of whether they are likely to be helpful for a cancer population. Although an acceptance-based approach is a potential target for treatment, this method would also be appropriate for other reasons. Where CBT emphasises cognitive modification, many of the thoughts

experienced by cancer patients in relation to their illness and fate are not necessarily 'maladaptive'; though the results of this study did suggest that actual disease status was not as associated with outcomes as appraisals, which may be influenced by a number of other factors. Given that challenging accurate but distressing thoughts about cancer-related issues such as death, disability, debt, or other issues may not be appropriate, an acceptance-based approach may be more appropriate in this context.

4.4. Further Strengths and Limitations

4.4.1. Correlational Research

Although correlational research is often criticised for an inability to show causation, it allows for investigation between existing variables, where it is not feasible or ethical to manipulate those independent variables; as in the case of cancer. However, there may be alternative explanations for the findings in this study based on its primarily correlational design, such as whether a third variable was influencing both response styles or outcomes. Furthermore, as linearity was not established between response styles and outcomes, it has not been determined whether responses lead to poorer outcomes or are the corollary of poorer outcomes, e.g. patients feeling depressed may tend towards withdrawal. However, the cross-lag analyses carried out did go some way to addressing whether there was a circular relationship between acceptance and outcomes, and the results indicated that there was not. Acceptance was shown to be predictive of future anxiety and functional quality of life, whereas these outcomes did not predict future acceptance. The use of follow-up data therefore allowed tentative speculation upon whether acceptance was a theoretical driver in its associations with outcome, which could not otherwise have been inferred from cross-sectional data taken at one point in time.

4.4.2. Further Limitations of Measures and Analyses

There was a mixture of both global and specific measures in the questionnaire battery, and some measures, such as the AAQ II and DAS, were not cancer-specific. However, it was hoped that the participant information sheet and wording between questionnaires was enough to orient participants to the

context of cancer; although this does not overcome the problem of item validity, as the wording of global items may not have been applicable to illness at all. ACT would suggest however, that avoidant response styles are likely to persist in many contexts, as a result of increasing experiential avoidance. Therefore, although Brief COPE items were not illness-specific, they were likely to indicate common patterns of responding that participants engaged in. TMT would imply that usual avoidant COPE styles may therefore have been provoked by the cancer-specific wording throughout the questionnaire, which served as a primer and anxiety-eliciting stimulus.

A further limitation of the research was that participants were not individually tracked throughout the analysis, and as a result it was not possible to see whether avoidant responses were not adversely associated with outcomes for some participants. Thus, the results speak to a general, overall effect and do not account for individual differences. The findings can therefore not be interpreted to mean that avoidant responses are never helpful for outcomes of distress and quality of life, or that they are always less helpful than acceptance. This will be context dependent, and dependent on whether the function the response serves is helpful for valued living. Indeed, many behavioural and ACT theorists will attest to the negatively reinforcing use of avoidance strategies, which alleviate anxiety in the short-term. In terms of cancer, traditional models of grief, such as that by Kübler-Ross (1969), incorporate an initial phase of denial, stating that the initial and proximal threat posed by death is initially too aversive to comprehend. Given the lack of individual analysis, the results of this research cannot say that this concept is likely to be incorrect, as denial may be a helpful strategy for some people, in some contexts. However, the point at which avoidant responses cease to be useful is theoretically when they become overly-relied upon in the long term, at the expense of valued living. In psychological terms, increased avoidance leads to a withdrawal from pleasurable and positively reinforcing activities, and this may be the mechanism by which distress and quality of life become negatively impacted upon.

4.4.3. Follow-Up

A strength of this study is that it had a longitudinal component in the follow-up questionnaire which was issued to consenting participants via an online link, three months after they had initially taken part. The majority of research in ACT and in cancer populations is of a cross-sectional design, restricting its capacity to address one limitation of questionnaire-based methodologies, in that participants' responses capture only a particular moment in time, and may therefore be affected by any number of extraneous variables. A follow-up therefore mitigated the impact of this to some extent by allowing analysis of whether significant changes had occurred between the first sample and those who participated in the follow-up. Furthermore, although individual participants' clinical and treatment progress was not tracked, the inclusion of a follow-up provided the possibility of re-measuring cancer-related experiences at a later phase in the cancer journey. For example, in the period between time points one and two, participants recruited from hospitals may have been transitioning into a different stage of care, entering end-of-life care, or perhaps entering out of treatment and into remission. The effect of the months following cancer treatment on distress and psychological wellbeing are documented in the literature (e.g. Costanzo et al., 2007). The follow-up therefore allowed the possibility of capturing these, for any participants who had either left treatment during the course of the study, or those whose cancer had been historic at both time points one and two. Measurement at two time points consequently allowed the effects of acceptance and response styles to be considered over time, and potentially at different phases of participants' cancer-related experiences. This in turn facilitated a broader range of analyses (e.g. cross-lag panel models), consideration of which factors might be influencing future outcomes, and potentially improved the generalisability of results to different, and changing, cancer contexts.

The three-month follow-up period was decided upon as a combination of what was practicable within the time frame of a DClinPsy study, and was also based on what was common in the cancer literature, where many studies had conducted follow-ups within the same time frame, e.g. Deshields et al., 2005. Although distress can be maintained for a full year or longer following cancer

treatment (Carlson, Waller, Groff, Zhong & Bultz, 2012), contextual factors also influenced the decision not to extend the period between times one and two. A limitation of this relatively short follow-up period was that a longer period may have allowed a greater amount of change to occur, for example changes in psychological outcomes, or changes in factors that might influence psychological change, such as finishing treatment. However, as we were recruiting from hospitals and a hospice, it was also likely that a lengthy follow-up would increase the chances of consenting participants not being able to take part after a protracted period, and in fact three participants recruited from the hospice did die in between times one and two.

The follow-up rate for the study was 53%, and although there are no universally-agreed thresholds for acceptable follow-up rates (Fewtrell et al., 2013), this could be considered a small- to medium-sized response rate. Whilst low follow-up rates may significantly compromise validity in studies which rely upon comparative analyses, such as randomised controlled trials, the follow-up data in this study was used only in examining secondary analyses. Although obtaining a smaller, and self-selected follow-up sample can introduce the risk of bias, for example if those who take part a second time do so because they are less depressed, this was protected against to some degree, as the follow-up data were used only to answer secondary research aims. Primary results were therefore obtained using the data from the primary data set, based upon the original 72 participants who initially took part.

4.5. Future Research

Given that the findings of this study provide preliminary support for the use of acceptance-based interventions with cancer patients, testing this notion is a clear direction for future research. Many studies into ACT-based processes consider more than one process at once, whereas this study has focused on acceptance; albeit the factor structure of the AAQ II may mean that some other processes were also measured. This study is therefore one of few that can provide a rationale for acceptance in cancer, which is thought to underpin many of the processes which make up psychological flexibility, and has here been shown to be predictive of future functioning. It is also unique in having

predictive, longitudinal data to support this suggestion. However, in order to be workable, increasing acceptance relies upon other processes such as mindfulness and moment-to-moment awareness, which have not been addressed here. Future work could therefore deliver acceptance to a cancer population, utilising these strategies, in order to see whether they have beneficial impacts upon distress and quality of life, as has been demonstrated in other healthcare populations.

4.6. Personal reflections

4.6.1. Choosing a research project

Upon starting the doctorate, we were soon encouraged to consider ideas for research projects. My initial thoughts were to conduct a study into complex trauma, though I soon found that many of the purported concepts I had found so captivating to read about, such as attachment and psychodynamic theories, were rather difficult to measure or operationalise, and did not easily lend themselves to research questions. Despite these initial interests leading to many thought-provoking theoretical discussions with a number of potential research supervisors, I struggled to translate them into practicable research projects and decided after several weeks to consider an alternative project.

Although cancer research may not seem like an obvious path down which my ideas could evolve, I had a pre-existing personal interest in psycho-oncology, stemming from time I had spent before the DClinPsy as a ward outreach volunteer in a cancer unit. Even though this unit was nationally renowned, there still lacked provision for psychological support and intervention, and I had come across many patients struggling with emotional distress. Contrastingly, I had also encountered many patients with remarkable and seemingly accepting attitudes towards their illnesses, and this contrast between apparent responses was, and remains, of fascination to me. What made each person different? What factors might influence the direction of someone's response to having cancer, and was this a stable response or did it fluctuate over time? It was thoughts such as these, combined with the support of my personal tutor, who has an interest in ACT, that led to the formation of my research project. Psycho-

oncology remains an area of interest for my future career, but it also remains under-resourced; a fact which has been brought to light on several occasions in the media since I began this project in 2013. I am pleased to have conducted research in an area of potential relevance to many of the projected 50% of people who might go on to develop cancer, and that the findings have practical and clinical implications. Furthermore, the project contributes to a sparse knowledge base around interventions and ACT processes in cancer, and provides tentative support for increasing acceptance as a psychological intervention in this population, where best practice and psychological treatment recommendations have yet to be established.

4.6.2. Ethical Reflections and Setting up the Study

It was a long and sometimes challenging journey from conceiving the project and its design, to finally conducting data collection over a year later. The first hurdle was applying for and receiving ethical approval for the study, and the rather challenging response I received when first presenting my project proposal to the local NHS Ethics Committee, who raised numerous concerns about conducting research with a cancer population. Although I was able to meet their requirements and answer their questions about ethical safeguarding, I have been struck on numerous occasions by the contrast between the opinions of people not involved in cancer care, who thought the work was important and interesting, and the anxieties and resistance I encountered from those involved in the care of cancer patients. For example, on a second occasion, I presented my proposed study to a meeting of Consultant Oncologists at a local hospital, in an attempt to gain their support as gatekeepers. Two particular members of staff had very strong and adverse reactions to my proposal, and I have found it interesting to reflect on this in relation to the death anxiety literature, which posits that looking after ill or dying patients can evoke in us strong emotional responses and reminders of our own mortality, which we may then react against. I wondered whether this apparent avoidance of death-provoking stimuli I witnessed in their reluctance to listen to my answers to their questions or to engage in two-way discussions, also led to their patients being denied the opportunity to talk openly about their experiences of having cancer, and whether this might exacerbate any patient

distress. The phenomenon of clinicians avoiding talking about death-related subjects has been reported in previous literature, and can also be seen at a societal level in the West, where we are largely avoidant of shared conversations about dying. Recent initiatives, such as Death Cafés, are beginning to emerge to break these taboos, in recognition of the negative impact this death phobia might have on us, irrespective of whether we are likely to die in the near future or not for many years to come.

Thankfully, some clinicians were willing to be gatekeepers for the study, and spoke to me about how the questionnaire may give patients permission to have important discussions with them about how they are feeling. The resistance I had encountered could have been through a desire to protect cancer patients from potentially distressing research questions, but given the lack of conclusive research on how best to intervene with cancer patients in distress, it also seems important to conduct research in this population. Furthermore, consent and information provided to participants gave them a clear choice as to whether or not to participate. The decisions surrounding the research project therefore had to minimise the risk of distressing participants as far as was possible, whilst also recruiting those patients who wished to contribute to the area of psycho-oncological research. Whilst carrying out data collection, I received two separate emails from participants outlining how important they thought it was that research is conducted in this population, which may speak to the fact that although we are anxious about engaging cancer patients in research about their psychological experiences, this does not mean it should not be done in a careful and ethically-sensitive manner.

4.6.3. Personal Development

Despite previously having obtained an MSc and a BSc, and having completed independent research projects during both of these degrees, my research knowledge and skills have augmented beyond my expectations as a result of this DClinPsy project, and the self-managed learning it has facilitated and required of me. The thesis project as a whole has felt like a huge step up from my earlier, post-graduate research project, particularly in regards to my understanding of research methodology and its philosophical underpinnings, the

ability to critique research, and my grasp of data analysis. In part, my learning has been due to the quality of the teaching and the high standards required of trainee research during training, but managing the research process somewhat independently has also contributed to my development as a research practitioner. This study has allowed me to learn about myself, and to overcome personal and practical challenges along the way. For example, the setting up and management of questionnaire distribution across four different sites in Nottinghamshire, and liaising with up to six different clinicians, required a lot of time, effort, and organisation. I would certainly consider my organisational processes more thoroughly if I were to undertake a similar project in the future. For example, using subfolders in email accounts sooner, and having a database of different clinicians and members of Ethics Research and Development (R&D) departments, so that I could keep track of who was from which Trust and where I was in the R&D process with each different team.

Although there were relatively few practical problems which emerged over the course of the two-year project, one oversight was that I had not considered how to match up participants whose first questionnaire had been paper-based (which I had coded with a hospital identifier), but who then went on to complete the follow-up online, where they generated a new pseudonym. This necessitated some painstaking work matching participants from the identifiers I had available to me, but thankfully most participants' email addresses contained their names, and their online forms could therefore be matched to their original, paper consent forms. If it had not been possible to reconcile the time one and time two data sets however, this oversight would not have prevented most of the secondary analyses from being carried out in this study, as individual change on outcome measures was not a component (though individual comparisons in demographic details were made, to explore whether there was any fluctuation which might give context to shifts in outcome measures). Failure to track participants effectively could seriously compromise the utility and outcomes of a research project, and this has been an important learning point that I can take forward when thoroughly planning the processes involved in future studies I might undertake.

The biggest research hurdle for me has been the writing up of the study, and managing my own avoidance. I have wondered whether the subject matter, specifically cancer and death-related experiences, has heightened my anxiety, thus explaining my initial avoidance of writing up the project. I attempted to apply the concept of acceptance to my own inner experiences as they occurred, such as noticing when I had thoughts about leaving the room and engaging in different activities, or noticing surges in anxiety and thoughts about not understanding the results. It helped during these times to focus on the bigger picture, i.e. that this project is a significant contribution to my qualification as a clinical psychologist, and focusing on my values in this way allowed me to tolerate the stress and discomfort I felt at times, in the knowledge that these experiences were part of an important process in working towards my goal.

Extended References

- Abeloff M. D., Armitage J. O., Lichter A. S., & Niederhuber J. E. (2000). *Clinical Oncology* (2nd ed). New York, NY: Churchill Livingstone.
- Abramowitz, J. S., Tolin, D. F., & Street, G. P. (2001). Paradoxical effects of thought suppression: A meta-analysis of controlled studies. *Clinical Psychology Review*, 21(5), 683-703.
- Adelbratt, S., & Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. *Palliative Medicine*, 14(6), 499-507.
- Andrykowski, M. A. & Manne, S. L. (2006). Are psychological interventions effective and accepted by cancer patients? Standards and levels of evidence. *Annals of Behavioral Medicine*, 32(2), 93-97.
- Arch, J. J., Eifert, G. H., Davies, C., Vilardaga, J. C. P., Rose, R. D., & Craske, M. G. (2012). Randomized clinical trial of cognitive behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for mixed anxiety disorders. *Journal of Consulting and Clinical Psychology*, 80(5), 750.
- Ashley, L., Smith, A. B., Keding, A., Jones, H., Velikova, G., & Wright, P. (2013). Psychometric evaluation of the revised illness perception questionnaire (IPQ-R) in cancer patients: Confirmatory factor analysis and rasch analysis. *Journal of Psychosomatic Research*, 75(6), 556-562.
- Baliousis, M., Rennoldson, M., & Snowden, J. A. (2015). Psychological interventions for distress in adults undergoing haematopoietic stem cell transplantation: A systematic review with meta-analysis. *Psycho-Oncology*, 25(4), 400-411.
- Beck, A. T. (1979). *Cognitive therapy and the emotional disorders*. Melbourne, Australia: Penguin Books.
- Becker, E. (1973). *The denial of death*. New York, NY: Simon & Schuster.

- Biglan, A., & Hayes, S. C. (1996). Should the behavioral sciences become more pragmatic? The case for functional contextualism in research on human behavior. *Applied and Preventive Psychology*, 5(1), 47–57. doi:10.1016/S0962-1849(96)80026-6
- Blackledge, J. T. (2007). Disrupting verbal processes: Cognitive defusion in acceptance and commitment therapy and other mindfulness-based psychotherapies. *The Psychological Record*, 57, 555-576.
- Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., . . . Zettle, R. D. (2011). Preliminary psychometric properties of the acceptance and action Questionnaire–II: A revised measure of psychological inflexibility and experiential avoidance. *Behavior Therapy*, 42(4), 676-688.
- British Psychological Society (2009). *Code of ethics and conduct. Guidance published by the ethics committee of the british psychological society*. Leicester: Author.
- Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the brief illness perception questionnaire. *Psychology & Health*, 30(11), 1361-1385.
- Bukberg, J., Penman, D., & Holland, J. C. (1984). Depression in hospitalized cancer patients. *Psychosomatic Medicine*, 46(3), 199–212.
- Cancer Research UK. (2014). *Cancer risk statistics*. London: Cancer Research UK. Retrieved from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk>
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International Journal of Behavioral Medicine*, 4(1), 92-100.
- Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annual Review of Psychology*, 61, 679-704.

- Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., . . . Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology*, 65(2), 375.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., . . . Brannon, J. (1993). The functional assessment of cancer therapy scale: Development and validation of the general measure. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 11(3), 570-579.
- Charmaz, K. (1980). *The social reality of death: Death in contemporary America*. Boston, MA: Addison Wesley Publishing Company.
- Chawla, N., & Ostafin, B. (2007). Experiential avoidance as a functional dimensional approach to psychopathology: An empirical review. *Journal of Clinical Psychology*, 63(9), 871-890.
- Ciarrochi, J., & Bailey, A. (2008). *A CBT-practitioner's guide to ACT: How to bridge the gap between cognitive behavioral therapy and acceptance and commitment therapy*. California, CA: New Harbinger Publications.
- Ciarrochi, J., Bilich, L., & Godsel, C. (2010). Psychological flexibility as a mechanism of change in acceptance and commitment therapy. In R. Baer (Ed.), *Assessing mindfulness and acceptance: Illuminating the process of change*. (pp. 51-76). Oakland, CA: New Harbinger Publications.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*. London: Routledge.
- Cook, R. D., & Weisberg, S. (1982). *Residuals and influence in regression*. London: Chapman & Hall.

- Costanzo, E., Lutgendorf, S., Mattes, M., Trehan, S., Robinson, C., Tewfik, F., & Roman, S. (2007). Adjusting to life after treatment: Distress and quality of life following treatment for breast cancer. *British Journal of Cancer*, 97(12), 1625-1631.
- Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-oncology*, 15(4), 306-320.
- Deshields, T., Tibbs, T., Fan, M., Bayer, L., Taylor, M., & Fisher, E. (2005). Ending treatment: The course of emotional adjustment and quality of life among breast cancer survivors immediately following radiation therapy. *Supportive Care in Cancer*, 13(12), 1018-1026.
- Eurobarometer. (2005). *Social Values, Science and Technology*. Retrieved from:
http://ec.europa.eu/public_opinion/archives/ebs/ebs_225_report_en.pdf
- Feros, D. L., Lane, L., Ciarrochi, J., & Blackledge, J. T. (2013). Acceptance and commitment therapy (ACT) for improving the lives of cancer patients: A preliminary study. *Psycho-oncology*, 22(2), 459-464.
- Fewtrell, M. S., Kennedy, K., Singhal, A., Martin, R. M., Ness, A., Hadders-Algra, M. . . . Lucas, A. (2013). How much loss to follow-up is acceptable in long-term randomised trials and prospective studies? *Archives of Disease in Childhood*, 93(6), 458-461.
- Field, A. (2013). *Discovering statistics using IBM SPSS statistics* (4th ed). California, CA: Sage.
- Flaxman, P. E., Blackledge, J. T., & Bond, F. W. (2010). *Acceptance and commitment therapy: Distinctive features*. East Sussex, UK: Routledge.
- Fledderus, M., Bohlmeijer, E. T., & Pieterse, M. E. (2010). Does experiential avoidance mediate the effects of maladaptive coping styles on

psychopathology and mental health? *Behavior Modification*, 34(6), 503-519. doi:10.1177/0145445510378379

Foley, K. M., & Gelband, H. (2001). Cross-cutting research issues: A research agenda for reducing distress of patients with cancer. In K.M. Foley & H. Gelband (Eds.), *Improving palliative care for cancer* (pp. 233-276). Washington, DC: The National Academies Press.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology*, 48(1), 150.

Francis, A. W., Dawson, D. L., & Golijani-Moghaddam, N. (In press). The development and validation of the comprehensive assessment of acceptance and commitment therapy processes (CompACT). *Journal of Contextual Behavioral Science*.

Freud, S. (1915). *Thoughts for the times on war and death. Collected papers*. London: The Hogarth Press.

Galli, U., Ettlin, D. A., Palla, S., Ehlert, U., & Gaab, J. (2010). Do illness perceptions predict pain-related disability and mood in chronic orofacial pain patients? A 6-month follow-up study. *European Journal of Pain*, 14(5), 550-558.

Galway, K.J., Black, A., Cantwell, M., Cardwell, C., Mills, M., & Donnelly, M. (2012). Psychosocial interventions to improve quality of life and emotional wellbeing for recently diagnosed cancer patients. *Cochrane Database of Systematic Reviews*, 11, CD007064.

Gerstein, D. R., & Johnson, R.A. (2000). Nonresponse and selection bias in treatment follow-up studies. *Substance Use & Misuse*, 35, 971-1014.

Gessler, S., Low, J., Daniels, E., Williams, R., Brough, V., Tookman, A., & Jones, L. (2008). Screening for distress in cancer patients: is the distress

thermometer a valid measure in the UK and does in measure change over time? A prospective validation study. *Psycho-Oncology*, 17(6), 538-547.

Gillanders, D., Ferreira, N., Bose, S., & Esrich, T. (2013). The relationship between acceptance, catastrophizing and illness representations in chronic pain. *European Journal of Pain*, 17(6), 893-902.

Gillanders, D. T., Sinclair, A. K., MacLean, M., & Jardine, K. (2015). Illness cognitions, cognitive fusion, avoidance and self-compassion as predictors of distress and quality of life in a heterogeneous sample of adults, after cancer. *Journal of Contextual Behavioral Science*, 4(4), 300-311.

Golijani-Moghaddam, N. (2014). Practitioner psychologists in palliative care: Past, present, and future directions. *Counselling Psychology Review*, 29(1), 29-40.

Gonen, G., Kaymak, S. U., Cankurtaran, E. S., Karslioglu, E. H., Ozalp, E., & Soygur, H. (2012). The factors contributing to death anxiety in cancer patients. *Journal of Psychosocial Oncology*, 30(3), 347-358.

Grant, L., & Kalus, C. (2010). A survey of applied psychologists in specialist palliative care: Settings, roles, and approaches. *Clinical Psychology Forum*, 208, 33-37.

Greenberg, J., Solomon, S., Pyszczynski, T., Rosenblatt, A., Burling, J., Lyon, D., & Simon, L. (1992). Assessing the terror management analysis of self-esteem: Converging evidence of an anxiety-buffering function. *Journal of Personality and Social Psychology*, 63(6), 913-922.

Greenberg, J., Pyszczynski, T., & Solomon, S. (1986). The causes and consequences of a need for self-esteem: A terror management theory. *Public self and private self* (pp. 189-212) Springer.

Gross, J. J. (1998). Antecedent-and response-focused emotion regulation: Divergent consequences for experience, expression, and physiology. *Journal of Personality and Social Psychology*, 74(1), 224.

- Guex, P. (1994). *An introduction to psycho-oncology*. London: Routledge.
- Gunzler, D., Chen, T., Wu, P., & Zhang, H. (2013). Introduction to mediation analysis with structural equation modelling. *Shanghai Archives of Psychiatry*, 25(6), 390-394. doi:10.3969/j.issn.1002-0829.2013.06.009
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18(2), 141-184.
- Hankins, M., Foster, C., Hulbert-Williams, N., & Breckons, M. (2013). The brief COPE in cancer research. *Psycho-Oncology*, 22, 22-23.
- Harris, R. (2006). Embracing your demons: An overview of acceptance and commitment therapy. *Psychotherapy in Australia*, 12(4), 70.
- Hayes, A. F. (2013). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. New York, NY: Guilford Press.
- Hayes, S. C. (1994). Content, context, and the types of psychological acceptance. Chapter in Hayes, S. C., Jacobson, N. S., Follette, V. M. & Dougher, M. J. (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 13-32). Nevada, NV: Context Press.
- Hayes, S. C. (2004). Acceptance and commitment therapy, relational frame theory, and the third wave of behavioral and cognitive therapies. *Behavior Therapy*, 35, 639-665.
- Hayes, S. C., Levin, M. E., Plumb-Villardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and commitment therapy and contextual behavioral science: Examining the progress of a distinctive model of behavioral and cognitive therapy. *Behavior Therapy*, 44, 180-198.

- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, 44(1), 1-25.
- Hayes, S. C. & Pankey, J. (2003). Psychological acceptance. In W. O'Donohue, J. Fisher, & S.C. Hayes (Eds.), *Cognitive-behavior therapy: Applying empirically supported techniques in your practice* (pp. 4-9). New York, NY: Wiley.
- Hayes, S., & Smith, S. (2005). *Get out of your mind and into your life*. California, CA: Raincoast Books.
- Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2011). *Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change* (2nd ed.). New York, NY: Guilford Press.
- Hegel, M. T., Collins, E. D., Kearing, S., Gillock, K. L., Moore, C. P., & Ahles, T. A. (2008). Sensitivity and specificity of the distress thermometer for depression in newly diagnosed breast cancer patients. *Psycho-oncology*, 17(6), 556-560.
- Helbig-Lang, S., Rusch, S., Rief, W., & Lincoln, T. M. (2015). The strategy does not matter: Effects of acceptance, reappraisal, and distraction on the course of anticipatory anxiety in social anxiety disorder. *Psychology and Psychotherapy: Theory, Research and Practice*, 88(4), 366-377.
- Herbert, J. D., & Forman, E. M. (2013). Caution: The differences between CT and ACT may be larger (and smaller) than they appear. *Behavior Therapy*, 44(2), 218-223.
- Herschbach, P., Keller, M., Knight, L., Brandl, T., Huber, B., Henrich, G., & Marten-Mittag, B. (2004). Psychological problems of cancer patients: A cancer distress screening with a cancer-specific questionnaire. *British Journal of Cancer*, 91(3), 504-511.

- Hoelter, J. W. (1979). Multidimensional treatment of fear of death. *Journal of Consulting and Clinical Psychology, 47*(5), 996.
- Hofmann, S. G., & Asmundson, G. J. (2008). Acceptance and mindfulness-based therapy: New wave or old hat? *Clinical Psychology Review, 28*(1), 1-16.
- Hofmann, S. G., Heering, S., Sawyer, A. T., & Asnaani, A. (2009). How to handle anxiety: The effects of reappraisal, acceptance, and suppression strategies on anxious arousal. *Behaviour Research and Therapy, 47*(5), 389-394.
- Hulbert-Williams, N. J., Storey, L., & Wilson, K. G. (2015). Psychological interventions for patients with cancer: psychological flexibility and the potential utility of acceptance and commitment therapy. *European Journal of Cancer Care, 24*, 15-27.
- Iverach, L., Menzies, R. G., & Menzies, R. E. (2014). Death anxiety and its role in psychopathology: Reviewing the status of a transdiagnostic construct. *Clinical Psychology Review, 34*(7), 580-593.
- Jacobsen, P. B., & Jim, H. S. (2008). Psychosocial interventions for anxiety and depression in adult cancer patients: Achievements and challenges. *CA: A Cancer Journal for Clinicians, 58*(4), 214-230.
- Kabat Zinn, J. (2003). Mindfulness-based interventions in context: Past, present, and future. *Clinical Psychology: Science and Practice, 10*, 144-156.
- Karekla, M., & Panayiotou, G. (2011). Coping and experiential avoidance: Unique or overlapping constructs? *Journal of Behavior Therapy and Experimental Psychiatry, 42*(2), 163-170.
- Kashdan, T. B., Barrios, V., Forsyth, J. P., & Steger, M. F. (2006). Experiential avoidance as a generalized psychological vulnerability: Comparisons with

coping and emotion regulation strategies. *Behaviour Research and Therapy*, 44(9), 1301-1320.

Kashdan, T. B., & Rottenberg, J. (2010). Psychological flexibility as a fundamental aspect of health. *Clinical Psychology Review*, 30(7), 865-878.

Kastenbaum, R. (2000). *The psychology of death*. New York, NY: Springer Publishing Company.

Kinderman, P., Read, J., Moncrieff, J., & Bentall, R. P. (2013). Drop the language of disorder. *Evidence-Based Mental Health*, 16(1), 2-3. doi:10.1136/eb-2012-100987

Kline, P. (1999). *The handbook of psychological testing* (2nd ed.) London: Routledge.

Kübler-Ross, E. (1969). *On death and dying: What the dying have to teach doctors, nurses, clergy and their own families*. Washington, DC: Taylor & Francis.

Kulpa, M., Ziętałewicz, U., Kosowicz, M., Stypuła-Ciuba, B., & Ziółkowska, P. (2016). Anxiety and depression and cognitive coping strategies and health locus of control in patients with ovary and uterus cancer during anticancer therapy. *Contemporary Oncology*, 20(2), 171.

Kuyken, W., Watkins, E., Holden, E., White, K., Taylor, R. S., Byford, S., . . . Dalglish, T. (2010). How does mindfulness-based cognitive therapy work? *Behaviour Research and Therapy*, 48(11), 1105-1112.

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York, NY: McGraw-Hill.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer publishing company.

- Lepore, S. J. & Coyne, J. C. (2015). Psychological interventions for distress in cancer patients: A review of reviews. *Annals of Behavioral Medicine*, 32(2), 85-92.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology*, 2, 7-30.
- Lillis, J., Hayes, S. C., Bunting, K. & Masuda, A. (2009). Teaching acceptance and mindfulness to improve the lives of the obese: A preliminary test of a theoretical model. *Annals of Behavioral Medicine*, 37, 58-69.
- Linehan, M. M. (1993). *Skills training manual for treating borderline personality disorder*. New York, NY: Guilford Press.
- Litman, J. A. (2006). The COPE inventory: Dimensionality and relationships with approach-and avoidance-motives and positive and negative traits. *Personality and Individual Differences*, 41(2), 273-284.
- Liverant, G. I., Brown, T. A., Barlow, D. H., & Roemer, L. (2008). Emotion regulation in unipolar depression: The effects of acceptance and suppression of subjective emotional experience on the intensity and duration of sadness and negative affect. *Behaviour Research and Therapy*, 46(11), 1201-1209.
- Low, J., Davis, S., Drake, R., King, M., Tookman, A., Turner, K., . . . Jones, L. (2012). The role of acceptance in rehabilitation in life-threatening illness. *Journal of Pain and Symptom Management*, 43(1), 20-28.
- MacKinnon, D. P., Fairchild, A. J., & Fritz, M. S. (2007). Mediation analysis. *Annual Review of Psychology*, 58, 593-614.
- Macmillan. (2015). *Psychological support: Evidence base*. Retrieved from: <http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newupdates/macvoice/winter2015/psychologicalsupportevidencebase.asp>

- Masedo, A. I., & Esteve, M. R. (2007). Effects of suppression, acceptance and spontaneous coping on pain tolerance, pain intensity and distress. *Behaviour Research and Therapy*, 45(2), 199-209.
- Massie, M. J. (2002). Prevalence of depression in patients with cancer. *NIH State of the Science Conference on Symptom Management in Cancer: Pain, Depression, and Fatigue*, 32, 57-71.
- Masuda, A., Hayes, S. C., Sackett, C. F., & Twohig, M. P. (2004). Cognitive defusion and self-relevant negative thoughts: Examining the impact of a ninety year old technique. *Behaviour Research and Therapy*, 42, 477-485.
- McCracken, L. M. (1998). Learning to live with the pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain*, 74(1), 21-27.
- McCracken, L. M. & Eccleston, C. (2003). Coping or acceptance: what to do about chronic pain? *Pain*, 105, 197-204.
- Menard, S. (1995). *Applied logistic regression analysis*. California, CA: Sage.
- Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. *Health Psychology*, 4(2), 115.
- Moos, R. H., & Holahan, C. J. (2003). Dispositional and contextual perspectives on coping: Toward an integrative framework. *Journal of Clinical Psychology*, 59(12), 1387-1403.
- Myers, R. (1990). *Classical and modern regression with applications*. Massachusetts, MA: Duxbury Thomson Learning.
- National Comprehensive Cancer Network (NCCN). 2007. *Clinical practice guidelines in oncology: Distress management, version 1*. Retrieved from: https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf
- National Institute for Clinical Excellence. (2004). *Improving supportive and palliative care for adults with cancer: The manual*. London: Author.

- Newell, S. A., Sanson-Fisher, R. W., & Savolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute*, 94(8), 558-584.
- Nipp, R. D., El-Jawahri, A., Fishbein, J. N., Eusebio, J., Stagl, J. M., Gallagher, E. R., . . . Greer, J. A. (2016). The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer*, 122(13): 2110-2116.
- Osatuke, K., Ciesla, J., Kasckow, J. W., Zisook, S., & Mohamed, S. (2008). Insight in schizophrenia: A review of etiological models and supporting research. *Comprehensive Psychiatry*, 49(1), 70-77.
- Payne, S. (1992). A study of quality of life in cancer patients receiving palliative chemotherapy. *Social Science & Medicine*, 35(12), 1505-1509.
- Pedhazur, E. J. & Schmelkin, L. P. (1991). *Measurement, design, and analysis: An integrated approach*. London: Psychology Press.
- Pessin, H., Galietta, M., Nelson, C. J., Brescia, R., Rosenfeld, B. & Breitbart, W. (2008). Burden and benefit of psychosocial research at the end of life. *Journal of Palliative Medicine*, 11(4), 627–632.
- Peters, L., Cant, R., Payne, S., O'Connor, M., McDermott, F., Hood, K., . . . Shimoinaba, K. (2013). How death anxiety impacts nurses' caring for patients at the end of life: A review of literature. *The Open Nursing Journal*, 10(7), 14-21.
- Pickersgill, M. D. (2014). Debating DSM-5: Diagnosis and the sociology of critique. *Journal of Medical Ethics*, 40(8), 521-525. doi:10.1136/medethics-2013-101762

- Rand, K. L., Cripe, L. D., Monahan, P. O., Tong, Y., Schmidt, K., & Rawl, S. M. (2012). Illness appraisal, religious coping, and psychological responses in men with advanced cancer. *Supportive Care in Cancer*, 20(8), 1719-1728.
- Reid, J. (2009). Conducting qualitative research with advanced cancer patients and their families: Ethical considerations. *International Journal of Palliative Nursing*, 15(1), 30-33.
- Ridner, S. H. (2004). Psychological distress: concept analysis. *Journal of Advanced Nursing*, 45(5), 453-551.
- Roth, S., & Cohen, L. J. (1986). Approach, avoidance, and coping with stress. *American Psychologist*, 41(7), 813.
- Rothbaum, F., Weisz, J. R., & Snyder, S. S. (1982). Changing the world and changing the self: a two-process model of perceived control. *Journal of Personality and Social Psychology*, 42, 5-37.
- Ruiz-Párraga, G. T., & López-Martínez, A. E. (2015). The role of experiential avoidance, resilience and pain acceptance in the adjustment of chronic back pain patients who have experienced a traumatic event: A path analysis. *Annals of Behavioral Medicine*, 49(2), 247-257.
- Schnider, K. R., Elhai, J. D., & Gray, M. J. (2007). Coping style use predicts posttraumatic stress and complicated grief symptom severity among college students reporting a traumatic loss. *Journal of Counseling Psychology*, 54(3), 344.
- Segal, Z., Williams, M., & Teasdale, J. (2002). *Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse*. New York, NY: Guilford Press.
- Skinner, E. A., Edge, K., Altman, J., & Sherwood, H. (2003). Searching for the structure of coping: A review and critique of category systems for classifying ways of coping. *Psychological Bulletin*, 129(2), 216.

- Smith, K. W., Avis, N. E., & Assmann, S. F. (1999). Distinguishing between quality of life and health status in quality of life research: A meta-analysis. *Quality of Life Research*, 8(5), 447-459.
- Solomon, S., Greenberg, J., & Pyszczynski, T. (2015). *The worm at the core: On the role of death in life*. London: Random House.
- Šoštarič, M., & Šprah, L. (2004). Psychological distress and intervention in cancer patients treated with radiotherapy. *Radiology and Oncology*, 38(3).
- Stanton, A. L. (2012). What happens now? psychosocial care for cancer survivors after medical treatment completion. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 30(11), 1215-1220. doi:10.1200/JCO.2011.39.7406
- Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., . . . Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*, 68(5), 875.
- Stanton, A. L., Danoff-burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: Hope and coping strategies as predictors of adjustment. *Psycho-oncology*, 11(2), 93-102.
- Stanton A. L., Leucken L. J., MacKinnon D. P. & Thompson E. H. (2012). Mechanisms in psychosocial interventions for adults living with cancer: opportunity for integration of theory, research, and practice. *Journal of Consulting and Clinical Psychology*, 81, 318–335.
- Stevens, J. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Hillsdale, NJ: Erlbaum.
- Stewart-Knight, K., Parry, R., Abey, A., & Seymour, J. (2012). Does the distress thermometer work? A systematic review of the evidence for its use and validity. *BMJ Supportive & Palliative Care*, 2, A30.

- Strömberg, A., & Jaarsma, T. (2008). Thoughts about death and perceived health status in elderly patients with heart failure. *European Journal of Heart Failure*, 10(6), 608-613.
- Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta-analysis. *Health Psychology*, 4, 249-288.
- Tennen, H., Affleck, G., Armeli, S., & Carney, M. A. (2000). A daily process approach to coping: Linking theory, research, and practice. *American Psychologist*, 55(6), 626.
- Törneke, N., Luciano, C., & Valvida Salas, S. (2008). Rule-governed behavior and psychological problems. *International Journal of Psychology and Psychological Therapy*, 8(2), 141-156.
- Urien, B., & Occidentale, D. B. (2004). On the role of materialism in the relationship between death anxiety and quality of life. *Advances in Consumer Research*, 35, 409–415.
- Van Oort, L., Schröder, C., & French, D. (2011). What do people think about when they answer the brief illness perception questionnaire? A 'think-aloud' study. *British Journal of Health Psychology*, 16(2), 231-245.
- Wegner, D. M. (1989). *White bears and other unwanted thoughts: Suppression, obsession, and the psychology of mental control*. New York, NY: Penguin Press.
- Wolgast, M., Lundh, L., & Viborg, G. (2013). Cognitive restructuring and acceptance: An empirically grounded conceptual analysis. *Cognitive Therapy and Research*, 37(2), 340-351.
- World Health Organization. (1997). *Measuring quality of life. The world health organization quality of life instruments*. Geneva: Author.
- Yalom, I. D. (2008). Staring at the sun: Overcoming the terror of death. *The Humanistic Psychologist*, 36, 283-297.

- Yost, K. J., Thompson, C. A., Eton, D. T., Allmer, C., Ehlers, S. L., Habermann, T. M., . . . Link, B. K. (2013). The functional assessment of cancer therapy-general (FACT-G) is valid for monitoring quality of life in patients with non-hodgkin lymphoma. *Leukemia & Lymphoma*, 54(2), 290-297.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(6), 361-370.
- Zimmermann, C., & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine*, 18(2), 121-128.

Extended Appendices

Appendix A

Clinical Gatekeeper Prompt Sheet

Accepting the 'Big C': Exploring the Acceptance - Quality of Life relationship in a cancer population.

Thank you for agreeing to help recruit participants for this study. This prompt sheet covers the study rationale and procedure, which may be useful when introducing the research to potential participants.

Overview

- There is a piece of research being carried out by clinical psychologists from Lincoln University. This research is not a part of our service but the researchers have approached us as we work with people who are affected by cancer.
- The researchers are inviting anyone who currently has, or who has had cancer, to complete a questionnaire. This is to find out more about the quality of life and the psychological experiences of those people who have (or have had) cancer.
- The researchers are investigating relationships between acceptance (which is 'a willingness to experience both pleasant and difficult thoughts and feelings') and other experiences that cancer patients have reported, such as anxiety.
- The study uses a questionnaire to ask about your personal experiences of cancer, and would require you to rate your own experiences of elements such as anxiety, stress, and coping. The results could help psychologists to understand the psychological impact of having cancer, and how they can better support patients.
- Whether you take part in this study, or not, will not affect your care in any way.

Practicalities

- The questionnaire should take 20-25 minutes to complete, and if you are interested in taking part I can give you a questionnaire pack*. It is important that you read the information sheet and take your time to consider whether to take part.
- Your responses can be posted back to the researcher in the stamped envelope provided.
- If you do take part, you will need to complete and sign the consent form attached to the questionnaire. The researchers have also asked you to

indicate on the consent form whether you would be happy to complete the questionnaire again in three months' time.

- Thank you very much for your interest in taking part. You can indicate on the questionnaire if you would like to be sent a link to the study results.

*Questionnaire pack given to interested participants = Participant information sheet, consent form, questionnaire and stamped addressed envelope.

Appendix B – Participant Information Sheet (paper version) – Time One

Participant Information Sheet

Title of Study: Accepting the 'Big C': Exploring the Acceptance - Quality of Life relationship in a cancer population

Name of Researcher: Lucinda Brabbins

We would like to invite you to take part in our research study. Before you decide whether to participate, we would like you to understand why the research is being done and what it would involve for you. Please read this information sheet and if you have any questions, ask a researcher, your nurse, or a member of your care team.

You can take away this information and if you decide to participate, you can either post back the consent form and questionnaires, or bring them back to the clinic on your next visit. The nurse or researcher will then store your responses securely.

What is the purpose of the study?

The purpose of this study is to explore whether there is a relationship between the therapeutic concept of acceptance and quality of life in a cancer population. This study will look for a relationship between acceptance and many other variables, such as distress, anxiety and coping.

Unlike much research into acceptance, this study is targeting a broad, rather than specific cancer population and will also include a 3-month follow-up after initial participation.

Why have I been invited?

You are being invited to take part because you have, or have previously had, a diagnosis of cancer. We are inviting current cancer patients and survivors to take part, with cancers of all sites, stages and points in treatment.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form before completing the questionnaires.

If you initially decide to take part but later change your mind, you are free to withdraw at any time, without giving a reason. Any decision not to take part or to withdraw from the study will **not** affect any care you may be receiving.

Please note that the final questions are about death and dying. If you find these, or any other questions, too distressing, you do not need to answer them.

What will happen to me if I take part?

If you agree to take part in the study and the three month follow-up, you will be asked to give some personal details, (e.g. name, telephone number, email address) which will be stored confidentially. You will also be asked to indicate whether you would prefer to be contacted via telephone or email. If you do not consent to the follow-up, you do not need to fill out the contact details on the consent form. Your consultant will be made aware of your decision to participate in the study.

The study will begin with some demographic questions (e.g. cancer site/grade, whether you are currently in/have had cancer treatment, time since diagnosis, whether you have accessed psychological support etc.). Following this, you will be asked to complete six questionnaires, which are designed to measure your attitudes towards and your experiences of different things (e.g. anxiety). We anticipate that this will take between 20-25 minutes in total.

Once you have completed the questionnaires, you will only be contacted again if you have consented to complete a follow-up questionnaire 3 months from the date you participate.

The researcher's details are available at the bottom of this information sheet should you have any questions at any time, before or after taking part.

What are the possible disadvantages and risks of taking part?

Due to the subject matter, some people may find answering questions about cancer and the realities of your situation distressing. It is therefore essential that you can access emotional support, through family, friends, cancer charities, psycho-oncology or your clinical team. If you are in treatment, your Cancer Nurse Specialist or another member of clinical staff will be able to refer you towards good sources of support (e.g. Macmillan). If you are no longer a cancer patient, your G.P. can provide a gateway to accessing support. Otherwise, many cancer charities have helplines, websites, and drop-in centres where you can find support. Three examples of these are:

Macmillan Helpline – 0808 808 0000 or www.macmillan.org.uk
Cancer Research UK – 0808 800 4040 or www.cancerresearchuk.org
Shine (support for those aged 20-50) www.shinecancersupport.co.uk

On Nottingham City Hospital site, you can access support from Maggie's on Hucknall Road, and from the Macmillan Cancer Information Centre in the Oncology Block.

What are the possible benefits of taking part?

The information we get from this study may help to highlight how useful psychological interventions could be for cancer patients. You may have seen recent calls for this in the media. The results may also help to show which aspects of psychological experience interventions could target.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher in the first instance, who will try to answer your questions. If you have a concern you wish to escalate, please contact the Research Supervisor. If this is an ethical concern, please contact Dr Patrick Bourke, Chair of the Lincoln University Research Ethics Committee. All contact details are at the bottom of this sheet.

Will my data be kept confidential?

Your data will either be collected via a paper survey or via an online survey tool (Qualtrics) on a computer, depending on how you have accessed the study. The survey data will be held online through Qualtrics, where it is inaccessible to any external party and available to view only by the researcher and research supervisors. Data from paper questionnaires will be stored in a locked filing cabinet at the University of Lincoln, to which only administrators, researcher and research supervisors will have access. Any follow-up questionnaires completed over the telephone will be recorded for data-gathering purposes. The recordings will be encrypted and stored securely at the University of Lincoln.

The results will remain password protected and stored for 7 years before being destroyed, in accordance with the Data Protection Act 1998. Where consent has been given for the follow-up, your personal data (name, telephone number) will be stored securely so that we are able to contact you after 3 months, after which time it will be destroyed. The exception to this is if you have asked to be emailed a link to the study results, in which case your details will be stored until that time.

The survey results (i.e. your responses) will be anonymised before being exported to a password-protected Excel spreadsheet. This anonymous data will then be subject to analysis using a computer statistics package.

We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw however, then the data collected so far cannot be erased once analysis has begun. However, your personal details would still be destroyed. This is because the questionnaire data will be pooled once the analysis begins, and it is therefore not possible to separate out an individual's responses. Should you wish to withdraw from this study at any time, please contact the Chief Investigator using the details below, and give your participant number. You will not need to give a reason why you wish to withdraw from the study.

What will happen to the results of the research study?

The results of this study will be written up as a thesis for a Doctorate in Clinical Psychology (DClinPsy), submitted in 2016. Participants will remain anonymous in the thesis and any further publications which may ensue. Participants will be asked at the start of the questionnaire whether they would like to be emailed a link to a results summary in 2016. If you would like access to these results, please indicate this on the questionnaire and a link to the study will be emailed to you in due course.

The results may also be published in a relevant journal (e.g. Journal of Psycho-Oncology), no sooner than 2017.

Who is organising and funding the research?

This research is being organised by the University of Lincoln.

Who has reviewed the study?

All proposed research in the NHS is assessed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Lincoln Ethics Committee and Lincoln Partnership Foundation Trust, as well as by the NHS Research Ethics Committee for this Trust.

Should you have any concerns regarding the ethical practice or conduct of this study, please contact Dr Patrick Bourke using the email address given below.

Contact Details

Chief Investigator: Lucinda Brabbins
Email: cancer.acceptance@gmail.com
Telephone: 07538 884432

Research Supervisor: Dr David Dawson
Email: cancer.acceptance@gmail.com

University of Lincoln Ethics Chair: Dr Patrick Bourke
Email: soprec@lincoln.ac.uk

Appendix C – Participant consent form



Trent Doctoral Training
Programme
in Clinical Psychology



Centre No:
Participant No:

PARTICIPANT CONSENT FORM

Title of Study: Accepting the 'Big C': Exploring the Acceptance – Quality of Life relationship in a cancer population

Name of Researcher: Lucinda Brabbins

Please tick the boxes below:

1. I confirm that I have read and understand the participant information sheet for this study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, by contacting the researcher. This will not affect any care I may be receiving. I understand that should I withdraw, the results collected so far cannot be withdrawn if data analysis has begun, but that my personal details will still be destroyed. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the researcher and research supervisor. I give permission for both parties to collect, store, analyse, and publish anonymous information obtained from my participation in this study. I understand that any personal details will remain confidential and stored securely for seven years. ☐
4. I understand that anonymous direct quotes from the survey may be used in the study reports and that any telephone calls will be recorded and stored securely for data analysis purposes. ☐
5. I understand that my consultant will be made aware of my decision to participate in this study. ☐
6. I agree to take part in the above study. ☐
7. I agree to take part in the follow-up in three months' time [optional]. ☐

Please sign:

Your name: Date __/__/__

Signature:

NB:

If you **DO NOT** agree to take part in the follow-up in three months' time, please indicate. You **DO NOT** need to leave contact details in this instance.

☐

If you wish to take part in the follow-up, please indicate how you would prefer to be contacted:

Telephone ☐ Telephone number.....

Email ☐ Email address.....

Appendix D – Final questionnaire – Time one

Acceptance - Quality of Life Questionnaire

Thank you for agreeing to take part in this research about your experiences of cancer. Please be sure to complete the consent form, and leave your contact details if you agree to the follow-up in three months' time.

The questionnaire should take 25-30 minutes to complete. If you find any of the following questions too distressing, please leave them blank. Sources of support can be found in your information sheet.

1. Personal Details

Your age group: ☐ 18-24 ☐ 25-34 ☐ 35-44 ☐ 45-54 ☐ 55-64 ☐ 65-74
☐ 75+

Your gender:

- ☐ Male
- ☐ Female
- ☐ Other

Are you currently, or have you previously been, participating in any other research?

- ☐ No
- ☐ Yes

If Yes, please give details:

Please indicate the highest level of education you have achieved:

- ☐ None
- ☐ Qualifications at level 1 or below

☐ GCSE or equivalent

☐ A levels or equivalent

☐ Higher education or equivalent

What, if any, has been your most recent occupation?

Do you wish to be sent an email link to the study results, once they are available?

☐ Yes

☐ No

If Yes, please leave your email address below:

Do you consider yourself to be spiritual/religious?

☐ No

☐ Yes

If yes, please describe:

Have you had any psychological support since being diagnosed with cancer?

☐ No

☐ Yes

If yes, please give a brief description of the type and source of support:

Have you been bereaved by cancer, or personally affected by a loved one having cancer?

☐ Yes

☐ No

Please state your consultant's name (if applicable):

2. Clinical Details

These questions concern the nature of your illness. Should you find any of them distressing in any way, you do not have to give an answer and should seek support from the sources specified in your information sheet.

If you have had cancer in the past, please fill this in relating to your *current* experiences. Please answer N/A to any questions which may no longer apply.

Which best describes your current situation?

☐ Having curative treatment

☐ Completed curative treatment

☐ Having palliative treatment

☐ Completed palliative treatment

☐ Other (please describe)

If you are aware of your cancer stage/grade, please indicate it below:

- ☐ I
- ☐ II
- ☐ III
- ☐ IV
- ☐ Don't know
- ☐ Not Applicable

If you have been told about your prognosis, please give details:

Do you know where your cancer is? Please describe:

Is this the first time you have had cancer?

- ☐ Yes
- ☐ No
- ☐ N/A

If no, how many previous occurrences of cancer have you had?

Thank you for your responses so far.

The following questions come from a battery of questionnaires which have been used in other psychological studies with cancer patients. If you find any of the questions too distressing, please do not answer them. Sources of support can be found in your information sheet.

Below is a list of statements that other people with your illness have said are important. **Please mark your responses (one per line), as they apply to the past 7 days.**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have nausea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my physical condition, I have difficulty meeting the needs of my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am bothered by side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am forced to spend time in bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get emotional support from my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get support from my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family has accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with family communication about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel close to my partner (or the person who is my main support)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you prefer not to answer this last question, please mark an X below

☐

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My work (including work at home) is fulfilling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to enjoy life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sleeping well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am enjoying the things I usually do for fun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am content with the quality of my life right now	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with how I am coping with my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am losing hope in the fight against my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry that my condition will get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate how much you agree or disagree with the following statements about your illness by checking the appropriate box:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
My cancer does not have much effect on my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have influence over my cancer (i.e. I can personally do things to improve my cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect to have this cancer for the rest of my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment can affect my cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experience symptoms from my cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am concerned about my illness ☐ ☐ ☐ ☐ ☐

I feel I understand my illness (i.e. I know what is 'wrong' with me) ☐ ☐ ☐ ☐ ☐

My illness affects me emotionally ☐ ☐ ☐ ☐ ☐

Is there anything that you think caused your illness? (List with the most important cause first):

1. _____
 2. _____
 3. _____
-

Read each item below and tick the box which comes closest to how you have been feeling in the past week.

	Most of the time	A lot of the time	From time to time, occasionally	Not at all
1. I feel tense or 'wound up'				

	Definitely as much	Not quite so much	Only a little	Hardly at all
2. I still enjoy the things I used to enjoy				

	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
3. I get a sort of frightened feeling as if something awful is about to happen				

4. I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
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5. Worrying thoughts go through my mind	A great deal of the time	A lot of the time	From time to time, but not too often	Only occasionally
--	--------------------------	-------------------	--------------------------------------	-------------------

6. I feel cheerful	Not at all	Not often	Sometimes	Most of the time
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7. I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
--	------------	---------	-----------	------------

8. I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
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9. I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
---	------------	---------------------------------------	-----------------------------------	----------------------------------

10. I feel restless as if I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
---	------------------	-------------	---------------	------------

11. I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
--	-----------------------	----------------------------	--------------------------------	---------------

12. I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
---	-------------------	-------------	----------------	------------

13. I can enjoy a good book, or radio, or TV programme	Often	Sometimes	Not often	Very seldom
---	-------	-----------	-----------	-------------

The following is a list of statements. Indicate how true each statement is for you, using the scale below:

1-----2-----3-----4-----5-----6-----7
 Never Very Seldom Sometimes Frequently Almost Always true
 true seldom true true true always true

	1	2	3	4	5	6	7
It's ok if I remember something unpleasant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My painful experiences and memories make it difficult for me to live a life that I would value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm afraid of my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about being unable to control my worries and feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My painful memories prevent me from having a fulfilling life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I am in control of my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotions can cause problems in my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It seems as if most people are handling their lives better than I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worries get in the way of my success	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My thoughts and feelings do not get in the way of how I want to live my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These items deal with the ways you've been coping with the stress in your life since you found out you had cancer.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been concentrating my efforts on doing something about the situation I'm in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying to myself "this isn't real"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to make myself feel better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting emotional support from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been giving up trying to deal with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been taking action to try and make the situation better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been refusing to believe this has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying things to let my unpleasant feelings escape	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting help and advice from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to help me get through it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to see it in a different light, to make it seem more positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I've been criticising myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to come up with a strategy about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been getting comfort and understanding from someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been giving up the attempt to cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been looking for something good in what is happening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making jokes about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been accepting the reality of the fact that it has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been expressing my negative feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to find comfort in my religion or spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to get advice or help from other people about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been learning to live with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been thinking hard about what steps to take	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been blaming myself for things that happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been praying or meditating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making fun of the situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your participation so far.

These final questions are about death and dying, and we appreciate that these may be difficult and upsetting for some people. Therefore, if you prefer not to answer these questions, please leave them blank. This will not affect your participation in this study, nor any care you may be receiving.

If a statement is true, or mostly true as applied to you, indicate True. If a statement is false or mostly false, as applied to you, indicate False.

	True	False
I am very much afraid to die	<input type="radio"/>	<input type="radio"/>
The thought of death seldom enters my mind	<input type="radio"/>	<input type="radio"/>
It doesn't make me nervous when people talk about death	<input type="radio"/>	<input type="radio"/>
I dread to think about having to have an operation	<input type="radio"/>	<input type="radio"/>
I am not afraid to die	<input type="radio"/>	<input type="radio"/>
I am/was particularly afraid of having cancer	<input type="radio"/>	<input type="radio"/>
The thought of death never bothers me	<input type="radio"/>	<input type="radio"/>
I am often distressed by the way time flies so very rapidly	<input type="radio"/>	<input type="radio"/>
I fear dying a painful death	<input type="radio"/>	<input type="radio"/>
The subject of life after death troubles me greatly	<input type="radio"/>	<input type="radio"/>
I am really scared of having a heart attack	<input type="radio"/>	<input type="radio"/>
I often think about how short life really is	<input type="radio"/>	<input type="radio"/>
I shudder when I hear people talking about a World War Three	<input type="radio"/>	<input type="radio"/>
The sight of a dead body is horrifying to me	<input type="radio"/>	<input type="radio"/>
I feel that the future holds nothing for me to fear	<input type="radio"/>	<input type="radio"/>

Thank you for your participation in this questionnaire, it is greatly appreciated. Please be sure you have filled out the **consent form** on the front page, and return it with your questionnaire using the envelope provided, or by handing the documents back to a member of the research team.

If you have found any part of this questionnaire distressing and would like further support, please speak to a member of your clinical team, or consider the sources of support listed in the information sheet. You will also find the researcher's contact details on your participant information sheet.

With kindest regards,
Lucinda Brabbins (Principal Investigator)

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Appendix E – Follow-Up Participant Information Sheet (paper version)

Accepting the Big C: Exploring the acceptance – quality of life relationship in a cancer population

Follow-up questionnaire participant information sheet

Why have I been invited?

A few months ago you participated in some research conducted by clinical psychologists at the University of Lincoln. Thank you for agreeing to participate in this follow-up questionnaire, which will help us to further investigate the relationships between quality of life and psychological variables such as acceptance, anxiety and coping.

If you would like to remind yourself about this research project, then please take a moment to read this information sheet. If you have any questions before or after completing the questionnaire, the researcher's contact details are available at the bottom of the sheet. This questionnaire is slightly shorter than the previous one, and will take approximately 15 minutes to complete.

The information we get from this study may help to highlight how useful psychological interventions could be for cancer patients. This is a current topic of interest, and calls for greater psychological support in cancer are regularly appearing in the media. The study results may also help to show which aspects of psychological experience interventions could target.

What is involved?

The questionnaire begins with some demographic questions (e.g. cancer site/grade, whether you are currently having cancer treatment etc.). Following this, you will be asked to complete a battery of questions, which are designed to measure your attitudes towards and your experiences of different things (e.g. anxiety). We anticipate that this will take 15 minutes in total. Please note that the final questions are about death and dying. If you find these, or any other questions, too distressing, you do not need to answer them and can leave them blank.

Do I have to take part?

It is entirely up to you to decide whether or not to take part in this follow-up questionnaire. You may still be happy to take part, or you may have changed your mind since consenting. If you initially decide to participate but later change your mind, you are free to withdraw at any time, without giving a reason. You can do this by contacting the researcher using the details below.

Potential risks

Due to the subject matter, some people may find answering questions about cancer and the realities of their situation distressing. It is therefore essential that you can access emotional support, through family, friends, or cancer charities. If you are in treatment, a member of clinical staff may be able to refer you towards good sources of support. If you are no longer a cancer patient, your G.P. can provide a gateway to accessing support. Otherwise, many cancer charities have helplines, websites, and drop-in centres where you can find support. Examples of these are:

Macmillan Helpline – 0808 808 0000 or www.macmillan.org.uk Cancer Research UK – 0808 800 4040 or www.cancerresearchuk.org Shine (support for those aged 20-50) www.shinecancersupport.co.uk Sue Ryder - support.sueryder.org

Data confidentiality

The questionnaire results will be anonymised before being exported to a password-protected Excel spreadsheet. This anonymous data will then be subject to analysis using a computer statistics package.

The results will remain password protected and stored for 7 years before being destroyed, in accordance with the Data Protection Act 1998. The exception to this is if you initially indicated that you would like to be emailed a link to the study results, in which case your details will be stored securely until the results are finalised.

Contact details

This thesis is part of a Doctorate in Clinical Psychology from the University of Lincoln. This study has been reviewed and given favourable opinion by University of Lincoln Ethics Committee.

The researcher's details are available below, should you have any questions at any time, before or after taking part. Should you have any concerns regarding the ethical practice or conduct of this study, please contact Dr Patrick Bourke using the details below.

Chief Investigator: Lucinda Brabbins
Email: cancer.acceptance@gmail.com
Telephone: 07538 884432

Research Supervisor: Dr David Dawson
Email: cancer.acceptance@gmail.com

University of Lincoln Ethics Chair: Dr Patrick Bourke
Email: soprec@lincoln.ac.uk

Appendix F – Follow-up Questionnaire

Acceptance - Quality of Life Follow-Up Questionnaire

Thank you for agreeing to take part in this follow-up questionnaire about your experiences of cancer. The responses you give will help us to further investigate whether there is a relationship between quality of life and psychological variables such as acceptance, anxiety and coping.

The questionnaire should take around 15 minutes to complete. If you find any of the following questions too distressing, please do not answer them and leave them blank. Sources of support can be found in the accompanying information sheet.

1. About you

Have you participated in any other research since taking part in the first questionnaire? If so, please give details:

Do you consider yourself to be spiritual / religious?

☐ No

☐ Yes

If yes, please describe:

Have you had any psychological support since being diagnosed with cancer?

☐ No

☐ Yes

If yes, please give a brief description of the type and source of support:

Have you been bereaved by cancer, or personally affected by a loved one having cancer?

☐ Yes

☐ No

2. Clinical Details

These questions concern the nature of your illness. Should you find any of them distressing in any way, you do not have to give an answer and should seek support from the sources specified in your information sheet.

If you have had cancer in the past, please fill this in relating to your *current* experiences. Please answer N/A to any questions which may no longer apply.

Which best describes your current situation?

☐ Having curative treatment

☐ Completed curative treatment

☐ Having palliative treatment

☐ Completed palliative treatment

☐ Other (please describe)

If you are aware of your cancer stage/grade, please indicate it below:

☐ I

☐ II

☐ III

☐ IV

☐ Don't know

☐ Not Applicable

If you have been told about your prognosis, please give details:

Do you know where your cancer is? Please describe:

Thank you for your responses so far.

The following questions come from a battery of questionnaires which have been used in other psychological studies with cancer patients. If you find any of the questions too distressing, please do not answer them. Sources of support can be found in your information sheet.

Below is a list of statements that other people with your illness have said are important. **Please mark your responses (one per line), as they apply to the past 7 days.**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have nausea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my physical condition, I have difficulty meeting the needs of my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am bothered by side effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am forced to spend time in bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get emotional support from my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get support from my friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My family has accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with family communication about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel close to my partner (or the person who is my main support)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my sex life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you prefer not to answer this last question, please mark an X below

☐

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My work (including work at home) is fulfilling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to enjoy life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have accepted my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sleeping well	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am enjoying the things I usually do for fun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am content with the quality of my life right now	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with how I am coping with my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am losing hope in the fight against my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry that my condition will	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

get worse

Please indicate how much you agree or disagree with the following statements about your illness by checking the appropriate box:

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
My cancer does not have much effect on my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I have influence over my cancer (i.e. I can personally do things to improve my cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect to have this cancer for the rest of my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My treatment can affect my cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experience symptoms from my cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I understand my illness (i.e. I know what is 'wrong' with me)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My illness affects me emotionally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there anything that you think caused your illness? (List with the most important cause first):

1. _____
 2. _____
 3. _____
-

Read each item below and tick the reply which comes closest to how you have been feeling in the past week.

1. I feel tense or 'wound up'	Most of the time	A lot of the time	From time to time, occasionally	Not at all
--------------------------------------	------------------	-------------------	---------------------------------	------------

2. I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
--	--------------------	-------------------	---------------	---------------

3. I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
---	---------------------------------	------------------------	-----------------------------------	------------

4. I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
--	---------------------------	-----------------------	----------------------------	------------

5. Worrying thoughts go through my mind	A great deal of the time	A lot of the time	From time to time, but not too often	Only occasionally
--	--------------------------	-------------------	--------------------------------------	-------------------

6. I feel cheerful	Not at all	Not often	Sometimes	Most of the time
---------------------------	------------	-----------	-----------	------------------

7. I can sit at ease and feel	Definitely	Usually	Not often	Not at all
--------------------------------------	------------	---------	-----------	------------

relaxed				
---------	--	--	--	--

	Not at all	Occasionally	Quite often	Very often
8. I get a sort of frightened feeling like 'butterflies' in the stomach				

	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
9. I have lost interest in my appearance				

	Very much indeed	Quite a lot	Not very much	Not at all
10. I feel restless as I have to be on the move				

	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
11. I look forward with enjoyment to things				

	Very often indeed	Quite often	Not very often	Not at all
12. I get sudden feelings of panic				

	Often	Sometimes	Not often	Very seldom
13. I can enjoy a good book, or radio, or TV programme				

The following is a list of statements. Rate how true each statement is for you, using the scale below:

1-----2-----3-----4-----5-----6-----7
 Never Very Seldom Sometimes Frequently Almost Always true
 true seldom true true true true always true

	1	2	3	4	5	6	7
It's ok if I remember something unpleasant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My painful experiences and memories make it difficult for me to live a life that I would value	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm afraid of my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry about being unable to control my worries and feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My painful memories prevent me from having a fulfilling life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am in control of my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Emotions can cause problems in my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It seems as if most people are handling their lives better than I am	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worries get in the way of my success	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My thoughts and feelings do not get in the way of how I want to live my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These items deal with the ways you've been coping with the stress in your life since you found out you had cancer.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been concentrating my efforts on doing something about the situation I'm in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying to myself "this isn't real"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to make myself feel better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting emotional support from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I've been giving up trying to deal with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been taking action to try and make the situation better	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been refusing to believe this has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been saying things to let my unpleasant feelings escape	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been getting help and advice from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been using alcohol or other drugs to help me get through it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to see it in a different light, to make it seem more positive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been criticising myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to come up with a strategy about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been getting comfort and understanding from someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been giving up the attempt to cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been looking for something good in what is happening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making jokes about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been accepting the reality of the fact that it has happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been expressing my negative feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to find comfort in my religion or spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been trying to get advice or help from other people about what to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been learning to live with it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been thinking hard about what steps to take	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been blaming myself for things that happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been praying or meditating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I've been making fun of the situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your participation so far.

These final questions are about death and dying, and we appreciate that these may be difficult and upsetting for some people. Therefore, if you prefer not to answer these questions, please leave them blank. This will not affect your participation in this study, nor any care you may be receiving.

If a statement is true, or mostly true as applied to you, indicate True. If a statement is false or mostly false, as applied to you, indicate False.

	True	False
I am very much afraid to die	<input type="radio"/>	<input type="radio"/>
The thought of death seldom enters my mind	<input type="radio"/>	<input type="radio"/>
It doesn't make me nervous when people talk about death	<input type="radio"/>	<input type="radio"/>
I dread to think about having to have an operation	<input type="radio"/>	<input type="radio"/>
I am not afraid to die	<input type="radio"/>	<input type="radio"/>
I am/was particularly afraid of having cancer	<input type="radio"/>	<input type="radio"/>
The thought of death never bothers me	<input type="radio"/>	<input type="radio"/>
I am often distressed by the way time flies so very rapidly	<input type="radio"/>	<input type="radio"/>
I fear dying a painful death	<input type="radio"/>	<input type="radio"/>
The subject of life after death troubles me greatly	<input type="radio"/>	<input type="radio"/>
I am really scared of having a heart attack	<input type="radio"/>	<input type="radio"/>
I often think about how short life really is	<input type="radio"/>	<input type="radio"/>
I shudder when I hear people talking about a World War Three	<input type="radio"/>	<input type="radio"/>
The sight of a dead body is horrifying to me	<input type="radio"/>	<input type="radio"/>
I fear that the future holds nothing for me to fear	<input type="radio"/>	<input type="radio"/>

Thank you for your participation in this follow-up questionnaire, it is greatly appreciated. Please return it to the research team using the envelope provided.

If you have found any part of this questionnaire distressing and would like further support, please speak to a member of your clinical team, or consider the sources of support listed in the information sheet. The researcher's contact details are also available on the participant information sheet.

Kind regards,
Lucinda Brabbins

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Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983. This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd), 389 Chiswick High Road, London W4 4AL. GL Assessment Ltd is part of the Granada Learning Group*

Appendix G – NHS Ethical approval letter



Health Research Authority

12 January 2015

Miss Lucinda Brabbins

University of Lincoln, 1st Floor, Bridge House, Brayford Pool LN6 7TS

Dear Miss Brabbins

NRES Committee East Midlands - Nottingham 1

Royal Standard Place Nottingham NG1 6FS Telephone: 0115 8839428

Study title:	Accepting the 'Big C': Exploring the Acceptance – Quality of Life relationship in a cancer population.
REC reference:	14/EM/1224
IRAS project ID:	152363

Thank you for your letter of 09 January 2015, responding to the Committee's request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Ms Penelope Gregory, NRESCommittee.EastMidlands-Nottingham1@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form,

protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study. Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity. For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation. Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster for online recruitment]	1.1	10 October 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Certificate]	1.2	30 December 2014
IRAS Checklist XML [Checklist_22102014]		22 October 2014
IRAS Checklist XML [Checklist_09012015]		09 January 2015
Letters of invitation to participant [Participant Invitation Text]	1.2	30 December 2014
Other [CV Second Supervisor Nima Moghaddam]	1.1	10 October 2014
Other [Letter to REC committee]	1.1	09 January 2015
Participant consent form [Participant Consent Form]	1.2	30 December 2014
Participant information sheet (PIS) [Participant Information Sheet]	1.2	30 December 2014
REC Application Form [REC_Form_22102014]		22 October 2014

Research protocol or project proposal [Research Protocol]	1.2	30 December 2014
Summary CV for Chief Investigator (CI) [CV Lucinda Brabbins]	1.1	10 October 2014
Summary CV for supervisor (student research) [CV Supervisor David Dawson]	1.1	10 October 2014
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research Schematic]	1.1	10 October 2014
Questionnaire [Participant questionnaire]	1.2	30 December 2014
Validated questionnaire [Participant Questionnaire -FACT-G]	1.2	30 December 2014
Validated questionnaire [Participant questionnaire -Brief IPQ]	1.2	30 December 2014
Validated questionnaire [Participant questionnaire -AAQ II]	1.2	30 December 2014
Validated questionnaire [Participant questionnaire -HADS]	1.2	30 December 2014
Validated questionnaire [Participant questionnaire -Brief COPE]	1.2	30 December 2014
Validated questionnaire [Participant questionnaire -Death Anxiety Scale]	1.2	30 December 2014

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

Notifying substantial amendments

Adding new sites and investigators

Notification of serious breaches of the protocol

Progress and safety reports

Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/> With the Committee's best wishes for the success of this project.

Yours sincerely **Dr Carl Edwards Chair**



Email: NRESCCommittee.EastMidlands-Nottingham1@nhs.net *Enclosures:*
"After ethical review – guidance for researchers" [SL-AR2] *Copy to: Professor Sara Owen Mrs Tracey McCranor, NHS (LPFT)*

14/EM/1224 Please quote this number on all correspondence

Appendix H – NHS Ethical approval letter for submitted study amendments



30 September 2015

Miss Lucinda Brabbins University of Lincoln, 1st Floor, Bridge House Brayford
Pool LN6 7TS

Dear Miss Brabbins

East Midlands - Nottingham 1 Research Ethics Committee

Royal Standard Place Nottingham NG1 6FS

Tel: 0115 8839269

Study title:	Accepting the 'Big C': Exploring the Acceptance - Quality of Life relationship in a cancer population.
REC reference:	14/EM/1224
Amendment date:	29 September 2015
IRAS project ID:	152363

Thank you for your letter of 29 September 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a “substantial amendment” as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Minor Amendment [Study Extension to September 2016]		29 September 2015
Other [Email of Notification]		29 September 2015

14/EM/1224: Please quote this number on all correspondence

Yours sincerely

Teagan Allen REC Assistant

Email: NRESCommittee.EastMidlands-Nottingham1@nhs.net

Copy to: Mrs Tracey McCranor, NHS (LPFT) Miss Lucinda Brabbins



Introduction

75% of cancer patients experience psychological distress, reduced quality of life and heightened levels of anxiety, grief, pain, and depression [1]. Acceptance and Commitment Therapy (ACT) [2] is reportedly effective for chronic pain, addictions, psychosis, diabetes, HIV, and epilepsy, but is under-researched in cancer populations. According to ACT, it is through our attempts to avoid and control difficult inner experiences that we inadvertently create a state of suffering. This can be alleviated through an alternative, accepting stance, involving a willingness to allow all thoughts and feelings to occur without judgement or avoidance. Given ACT's efficacy for other health populations [3], acceptance may be an effective and response style for cancer patients, and a potential alternative to the avoidant response styles associated with poorer psychological and functional outcomes [4-5].

Aims

The primary aims of this study were 1) to discover whether acceptance was related to quality of life and distress outcomes in cancer patients, and 2) whether acceptance moderated any relationship between cancer appraisal, and quality of life and distress outcomes (Figure 1). Secondary aims were to examine 3) whether sample characteristics and alternative response styles were related to quality of life and distress outcomes, and 4) any temporal relationships between acceptance and outcomes, across time points one and two.

Method

72 participants with direct experience of a range of cancers completed a battery of clinical questions and six standardised questionnaires: Brief IPQ, HADS, FACT-G, Brief COPE, AAQ II, Death Anxiety Scale (DAS). 31 participants repeated the measures after three months. Five avoidant coping styles were entered into regression models alongside the Brief IPQ and AAQ II, for time one and time two data. Moderation analyses explored the impact of moderation on cancer appraisals and outcome variables at both time points. Cross-lag panel models explored whether acceptance was predictive of outcomes over time.

References:

- [1] Cancer Research UK. Cancer risk statistics. London 2014.
- [2] Hayes S, Strosahl K, Wilson K. Acceptance and commitment therapy: an experiential approach to behavior change. 2nd ed. New York: Guilford Press. 2003.
- [3] A-Tjak, JGL, Davis, ML, Morina, N, Powers, MB, Smits, JAJ, Emmelkamp, P MG. A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychother Psychosom*. 2014; **84**(1): 30-36.
- [4] Hulbert-Williams NJ, Storey L. Psychological flexibility correlates with patient-reported outcomes independent of clinical or sociodemographic characteristics. *Support Care Cancer*. 2015; **24**(6): 2513-2521
- [5] Nipp RD, El-Jawahri A, Fishbein JN, Eusebio J, Stagl JM, Gallagher ER, et al. The relationship between coping strategies, quality of life, and mood in patients with incurable cancer. *Cancer*. 2016; **122**: 2110-16.

Results

Results showed acceptance was a significant explanatory variable in social and emotional quality of life outcomes, and also had significant explanatory power for outcomes of depression, anxiety, and death anxiety, in a negative direction. Behavioural disengagement was also a significant contributor to depression outcomes, though acceptance explained a greater proportion of variance for the depression model. Avoidant response styles were negatively correlated with quality of life, and positively correlated with distress on all outcomes. Although acceptance was not a significant moderator in the relationship between illness perceptions and outcomes, acceptance was predictive of anxiety and quality of life at time two.

Discussion

Avoidant response styles such as denial, behavioural disengagement, and self-distraction, showed a pattern of moderate to strong negative correlations with quality of life, and significant positive correlations with distress outcomes in the cancer population. Contrastingly, acceptance was an independent explanatory variable of quality of life and distress outcomes, in directions consistent with psychological health, and also demonstrated predictive power for these outcomes over time, over and above the influence explained by either physical disease characteristics or cancer appraisals. In contrast to psychodynamically-informed death anxiety literature, which suggests that inner experiences resulting from threats to mortality must be avoided, results suggest the opposite: that accepting cancer-related inner experiences has positive implications for quality of life and psychological distress outcomes.

The findings support ACT's hypothesis that experientially avoiding and struggling against experiences maintains distress [2]. Furthermore, results also show that many response styles that might be incorporated into more traditional cognitive behavioural or expressive therapies, e.g. active coping, emotional support, planning, positive reframing, and venting, are not associated with positive outcomes in cancer patients, and that targeting acceptance rather than cognitive reappraisal is indicated as a psychological intervention.

SYSTEMATIC REVIEW

Mindfulness-based therapies in palliative cancer patients: A systematic review of use and effectiveness

Lucinda J. Brabbins ^{1*}

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This paper was written in preparation for submission to the journal *Psycho-Oncology*.

Abstract

Objective. This systematic review aims to critique the current evidence for the use and effectiveness of mindfulness-based therapies in palliative cancer care.

Methods. A thorough search of the literature was conducted using electronic databases and hand searching, following systematic review methods. Efforts were made to identify unpublished, 'grey' literature. Results were filtered and evaluated according to pre-determined inclusion and exclusion criteria, before being synthesised and presented.

Results. Six papers were identified as meeting the criteria. Four were published after 2007, and two were based on the same study (one being a six month follow-up). Three studies were randomised controlled trials, and two were pretest-posttest designs. Results found a dose-response effect between time practicing mindfulness and improved psychological outcome. Significant effects for lessened anxiety, depression, and pain were also found. Methodological limitations were identified, and modifications to mindfulness interventions suggested.

Conclusions. Mindfulness has promise as an intervention for this population, both in group settings and as a self-administered intervention. Further adaptations and component studies are recommended.

Keywords: Cancer, Oncology, Mindfulness, Palliative, Terminal, Intervention

Background

Mindfulness is defined by Kabat-Zinn [1] as 'the awareness that emerges through paying attention on purpose, in the present moment and non-judgementally to the unfolding of experience' (p.145). Attempts to achieve this state of consciousness stem from Buddhist tradition, and it is a skill developed through the practice of mindfulness meditation. In recent years, the reported benefits of mindfulness have seen its inclusion within formal, structured interventions such as mindfulness-based cognitive therapy (MBCT), mindfulness-based stress reduction (MBSR), Dialectical Behaviour Therapy (DBT), and Acceptance and Commitment Therapy (ACT) [2, 3-6]. However, Kabat-Zinn cautions against the temptation to manualise and apply mindfulness to clinical problems, without understanding the context within which it belongs. For example, in its heightened popularity, decontextualised mindfulness may be offered to a clinical population as a 'curative' intervention, aiming to fix problems - as healthcare patients have come to expect. However, a true mindful approach would require a complete departure from this curative perspective, invoking a willing openness to accept both good and bad experiences, rather than trying to forcibly eliminate unpleasant ones.

Mechanisms of action

Shapiro [7] highlighted the need to understand how mindfulness works, given that studies have demonstrated its effectiveness in anxiety disorders, chronic pain, stress, and mood disturbance in cancer patients [8-11]. Shapiro suggests that mindfulness leads to changes when three fundamental components - intention, attention, and attitude - are cultivated. Specifically, these refer to: a personal vision to be achieved by obtaining a mindful state; the observation of internal and external states without interpretation; and approaching these observations in a compassionate and curious manner. These axioms lead to 'reperceiving,' i.e. a shift in perspective, which underpins the changes that practicing mindfulness can reportedly bring [8-11]. Shapiro suggested that reperceiving leads to four further direct mechanisms of action: self-regulation and management, flexibility, values clarification, and exposure. A review by Hölzel et al. [12] showed that more recent research has lent support to these theorised mechanisms (with the exception of values clarification), and also included findings from neuroimaging studies. Here, mindfulness has been shown to produce neuroplastic changes across several areas of the brain, including the amygdala; where activity has decreased in line with increased emotional regulation in mindfulness [13]. The same study concluded that by consciously influencing mental processes, humans can influence the 'electrochemical dynamics of their brains.'

The concept of reperceiving has parallels within other psychological approaches, such cognitive therapy, which works to shift a person's appraisal of a situation in order to change their emotional and behavioural responses [14]. This approach is often applied within cognitive behavioural therapy (CBT), which has a vast evidence base and, like mindfulness, has also been shown to be effective in anxiety, depression, and chronic health conditions [15,16]. Studies have compared mindfulness-based and cognitive behavioural interventions, finding them both effective in treating anxiety disorders, and differing in the aspects they impacted most on: worry and anxious arousal,

respectively [17]. This level of compatibility means that mindfulness has been incorporated into a CBT approach, where re-perceiving is referred to as 'decentring', and has also been integrated with CBT in the form of MBCT [3]. However, to heed concerns about maintaining the context surrounding mindfulness interventions, the roles of intention, attention, and attitude should all be emphasised, rather than giving precedence to the role of attention, as CBT can do. Further research and dismantling studies would help to determine more precisely which active components of mindfulness are the most effective, and to continue elaborating on theories about its mechanisms of action.

MBCT represents one way in which mindfulness can be applied, and was recently developed as a group programme to target vulnerability to future relapse in depression. More specifically, it aims to foster attention and new ways of relating to the negative thoughts which precede depressive relapse; thoughts identified as common amongst depressed people by Beck [18]. It is also helpful in non-clinical populations, for people experiencing anxiety and stress [19]. Evidence for MBCT is promising based on the results of randomised controlled trials (RCTs) thus far. However, it is also a nascent intervention and as such there are not yet enough RCTs to demonstrate generalisable results [20,21].

MBCT evolved out of MBSR, a psycho-educational and skills-based programme, combining yoga exercises with mindfulness meditation. MBSR takes place over eight, weekly, two-and-a-half hour group sessions (including one whole retreat day), and requires daily practice using recordings. Mindfulness skills such as body scan and sitting meditation are taught, and yoga stretches help participants to become aware of bodily sensations [22]. MBCT combines these factors with cognitive therapy, has smaller class sizes, and a more homogenous group demographic, e.g. similar physical conditions. Although developed and effective for sufferers of chronic pain and stress-related problems [9], MBSR has also been shown to be effective for fibromyalgia, HIV, anxiety, and in reducing sleep, stress, low mood, and fatigue in cancer patients [23-26].

Cancer patients present a unique and heterogeneous population due to the variability of the disease and the impact of different factors (e.g. treatment side-effects, operations, hospitalisation, prognosis) upon patients' lives. Cancer sufferers are therefore at increased risk of psychological distress, anxiety, and depression; with some estimates of depression and distress as high as 30%-45% [27,28]. Certain types of cancer, e.g. advanced prostate, have unique challenges for patients, due to the impact of hormonal treatments on factors such as mood disturbance, cognitive impairment, hot flushes, and sexual dysfunction. The impact of these changes puts men with advanced prostate cancer at greater risk of psychological distress and suicide [29,30]. The psychological effects of advanced cancer are not limited to its occurrence in the prostate: advanced cancer is associated with cancer-related fatigue and pain across multiple sites [31]. Patients also suffer from anxiety, depression, and poor quality sleep - the latter correlating with worse pain and poorer quality of life [32, 33].

Given the high distress levels amongst the palliative population, there is a clear rationale for psychological intervention: a claim supported by the NICE guidelines for palliative care [34]. This need is further emphasised by the discrepancy in numbers between patients who experience distress (45%) and those who receive psychological support (10%) [28]. The unique needs of palliative patients and the logistical challenges they face must be accommodated by any intervention offered. Given the potential flexibility of mindfulness interventions, their lower impact on staff time [28], and the existing evidence for their effectiveness, they would logically seem suitable for a palliative population.

Applications of mindfulness-based therapies to cancer patients reflects a wider trend for the use of alternatives to medication, awareness of psychological and physical wellbeing, and the development of a more holistic approach to cancer treatment [26]. Although the evidence for mindfulness in cancer is becoming well-established, comparatively there exist far fewer studies and reviews focusing on a population with advanced, terminal or late stage cancer; despite the higher levels of distress they may face [35, 29]. Given that studies have acknowledged differences in wellbeing across the cancer trajectory [26], and the proposed adaptation of interventions for advanced cancer [36], it is necessary to gain a better understanding of how mindfulness is applied to this population, and whether or not it is effective. It thus seems timely to answer calls to consider different stages of cancer in future research [36], by reviewing the existing evidence for mindfulness-based therapies in palliative cancer.

This review will aim to synthesise current research in this area, to evaluate the use of mindfulness-based therapies (i.e. how and where they are implemented, and in what form), alongside their effectiveness, for a palliative cancer population.

Methods

Searching

A thorough search of the literature was conducted via electronic databases, and hand-searches of journals and reference lists. Six biomedical, life and behavioural sciences, mental health, and nursing electronic databases were identified as being appropriate for the area of research.

EMBASE, MEDLINE, psycINFO, CINAHL and SCOPUS were accessed, and grey literature was searched via PROQUEST. Searching electronic databases alone is unlikely to identify all relevant literature available [37], and for this reason four relevant journals were hand searched: Journal of Psycho-Oncology, Journal of Alternative and Complementary Medicine, Journal of Advanced Nursing and Journal of Integrative Cancer Therapies.

Search terms

The final search terms used were:

1. *Mindfulness, meditat**, *“mindfulness meditation,” MBCT, MBSR, MBSR-C, “Acceptance and Commitment Therapy”*

2. *Therap**, *treatment*, *intervention*, *psych**, *training*, *practice*, *practise*

3. *Cancer*, *oncology*, *tumo#r*, *neoplasm*

4. *Dying*, *terminal*, *palliative*, “*stage 4*,” “*stage four*,” “*stage IV*,” “*grade d*,” “*end of life*,” *metasta**, *incurable*, *advanced*

(NB: See Appendix II for a visual representation of these search terms.)

The Boolean operator OR was used between each separate word or phrase, and AND was used to include all four strings of words in each search. Limits were set to only include English language and a human, adult population. These limits were decided on the basis of a) readability, and b) evidence of large differences between adult, adolescent, and childhood cancers, both biologically, i.e. disease site and aggression, and in terms of impact and survival rate [38].

Search terms were decided by considering what would be necessary to answer the research question, and after reviewing keywords in existing literature on cancer, psychological interventions, and mindfulness.

Neoplasm and *tumo#r* were added to the search terms following a pilot search, which helped to highlight keywords and medical subject (MeSH) headings commonly used in studies using a cancer population. Acceptance and Commitment Therapy (ACT) was also included after the pilot search, in order to capture any studies that used mindfulness, but described its use as an ACT intervention.

Selection

Filtering took place in three phases, each time reducing the number of papers to be included at different stages. 322 papers were initially identified, and six were included in the final review. A visual representation of this searching and filtering process is displayed in Figure 5 below.

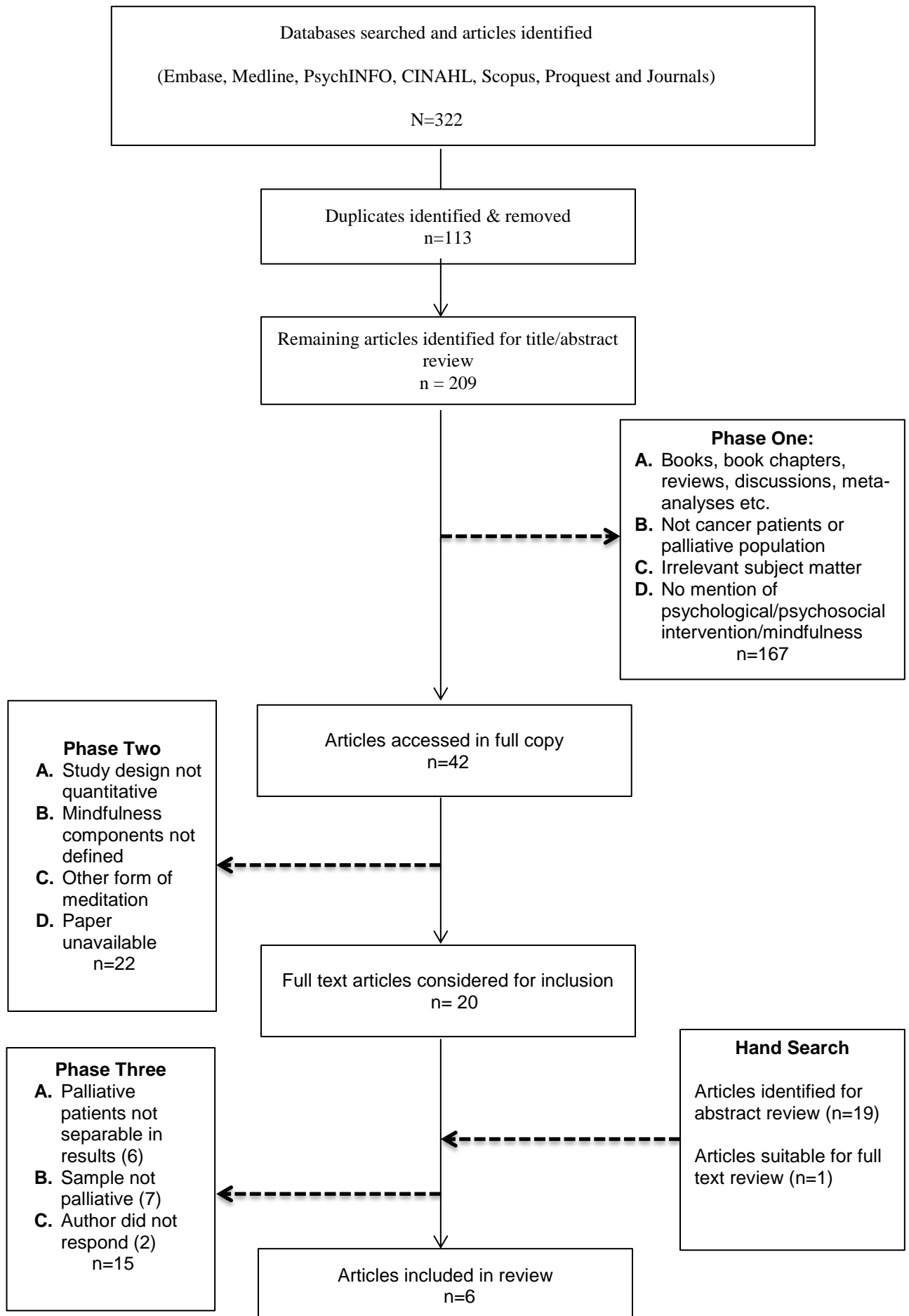


Figure 5: A Quorum diagram outlining the filtering process

Inclusion criteria

Inclusion criteria were kept as broad as possible, given that using a palliative population was likely to lead to lower numbers of articles [35] (as discussed above). For this reason, no time limit was placed on the searches, and all types of cancer were included, provided there was an adult, palliative population, of any age (above 18), gender or race. For this review, palliative is taken to be interchangeable with any other word in search string four, i.e. it refers to patients whose cancer is incurable and will result in loss of life. There also needed to be reference made to mindfulness-based therapy mentioned at phase one, matching any of the search terms in search string one, or similar alternatives. At phase two, the properties of the mindfulness therapies were more extensively scrutinised (see below).

Exclusion criteria

Exclusion criteria will be outlined by phase, so as to elucidate the filtering process.

Phase one - Studies were excluded on the basis of non-adult populations, and non-English write-ups, as explained above. Only primary research was considered for this review, and other forms of material (e.g. book chapters, magazine articles, previous reviews) were excluded on this basis. Primary research involves detailed reporting of both results and methodology, therefore enabling the question as to the effectiveness of mindfulness interventions to be answered.

Given the inclusion criteria, any articles that were not about the subject of a mindfulness therapy, a cancer population, or, those that were explicitly not palliative (e.g. early stage cancer, patients in remission, or 'survivors') were excluded, as they were not relevant to the research question.

Phase two – Studies which were not quantitative were excluded. Qualitative studies do not necessarily intend to produce generalisable findings [43], whereas this review aims to synthesise findings across different papers in order to contribute to discussion on the rationale and evidence for mindfulness-based therapies in palliative cancer care. As demonstrated by the hierarchy of evidence [44], quantitative studies are more commonly used than qualitative studies to inform healthcare interventions, and were therefore selected because of their capacity to directly impact upon development within palliative cancer care.

Studies were excluded if their intervention was not within the context of the key concepts of mindfulness, e.g. moment-to-moment, non-judgemental awareness. For example, studies which had been selected due to containing meditation were later excluded if they were not underpinned by mindfulness principles. These principles could be discussed within the background of a study, or described explicitly to participants in the study - either was taken to mean that the article referred to the version of mindfulness defined and

propagated by Kabat-Zinn [1], and the quality of the intervention would then be assessed within this review. Similarly, other types of meditation, e.g. transcendental meditation, were also excluded as they are not mindfulness-based.

Several papers from the grey literature database could not be retrieved, and were also excluded at this stage.

Phase three – Studies were excluded at this stage if palliative patients were included as part of a wider sample, but their results were not reported separately, or subjected to statistical analysis (n=6). This was in order to ensure that any reported findings were attributable and relevant to the palliative subject group. Four further studies transpired not to have palliative samples, e.g. had defined cancer as ‘advanced,’ but had integrated stage III and IV results on closer inspection. One further study may have been relevant for final inclusion in the review, but the full-text article could not be retrieved and the author could not be contacted [45].

Two study protocols were identified for proposed RCTs, but were not included within the final articles as the lack of results would not help to answer the question of effectiveness [32,41].

Minimising bias

There is a bias in research towards studies which report positive findings, and they also have an increased likelihood of being selected for publishing [46]. Therefore, an attempt to minimise bias was made by conducting a search of the grey literature and reading unpublished studies. However, bias is acknowledged in only including results published in the English language, which may restrict findings from other countries and cultures, and present further bias considering that positive findings are more likely to be reported in English language journals [46]. Furthermore, only one researcher coded and filtered the articles included in this review, rather than two, as recommended [47].

Data extraction

A coding framework was used to obtain relevant information from the six remaining studies, to help inform thinking about the effectiveness and use of interventions. The components of this framework can be seen in the table headings in Tables 8-10 (see appendices). Evaluating the methodological quality of studies is fundamental when considering their findings, and a quantitative quality assessment tool, the Effective Public Health Practice Project, (EPHPP) [48] was used to aid this process. The EPHPP has high content and construct validity, and was developed for use in evaluating public health initiatives and interventions.

Results

The search initially identified 322 papers, of which 113 were duplicates and were removed. 209 papers were therefore identified for abstract review, and following filtering, 42 of these were identified in full text for review. 20 of these

papers were considered for inclusion, and hand searching of their reference lists identified a further six further papers for full-text review. One further RCT [40] was identified here, whose six-month follow-up paper had already been reviewed [26]. Both are included, as they have slightly differing authors and, despite their content mostly overlapping, one is more detailed overall*. Of these 20 papers, a further 15 were excluded, and six papers are therefore included in the final review [26,28,35,39,40,42].

*Papers [40,26] have been combined in the results tables (see appendices), and will be referred to in the write up as one study [26], for continuity.

The remaining papers comprised three randomised controlled trials (RCTs) and two single group, pretest-posttest designs. All studies used quantitative methods, but only two [26,42] did not also incorporate a qualitative element, either through focus groups or semi-structured interviews, to gauge participants' opinions and responses following the intervention. Quality ratings were allocated to each study using an assessment tool, to help to assess methodological robustness, though interpretation and quality assessment will not be limited to these scores (Appendix A, Table 9). Results are presented in Tables 8-10 (see appendix A), separated into study characteristics and key findings, methodological properties, and intervention characteristics. A narrative synthesis of the findings is provided below.

i. Study characteristics

Only two studies were conducted longer than a decade ago [26], with the remaining four taking place between the years 2007-2012.

Participants

Only one study [26] recruited a palliative sample from within a wider cancer sample, where the palliative sub-population comprised 21% of overall participants. There were 215 participants in total across all studies, of whom 60% were female and 40% were male. The mean age of participants ranged from 52-72.4, with a total mean of 64 years old. Only one study provided ethnicity statistics, within which the majority of participants were Caucasian (82%) and the remainder were African American (18%) [35]. The education level overall was high, except for in Hong Kong, where 81% of participants had education equal to or below primary school level [42]. Three studies had speaking English as an inclusion criterion [39,35,28], and the same three also specified that participants could not have a psychiatric disorder. There was a wide range of countries represented, spanning four continents, with no two studies taking place in the same country.

The most common cancer was breast, reflecting the higher number of women in the studies. Two studies included mixed cancer sites [26,42], one solely included metastatic breast [35], one solely prostate [39], and one included metastasised breast and prostate [28]. Terms used to refer to the stage of participants' cancer differed between studies, with only two studies using the same term, 'metastatic' [28,35], and the others using 'stage 4' [26], 'advanced' [39] and 'terminal' [42].

Randomised Controlled Trials (RCTs)

Of the three RCTs, two had waiting-list control groups [26,28] (the interventions were delivered to controls at 7 weeks and 6 weeks respectively), and one had a no treatment control group [42]. Descriptions of the randomisation process briefly mentioned fixed randomisation using a number table [26], randomisation by balloting [42], and one did not report the method used [28]. All three RCTs were unblinded, and none reported a position of equipoise. Some participants were given information to use if they wished to increase their knowledge of mindfulness [26], and another reported that some participants actively participated in extra palliative activities, such as psychotherapy, at the hospital [42]. All three studies took baseline measures and demographic information from participants prior to the randomisation process, and one matched participants in the two groups on socio-demographic variables [28].

Cohort studies

Two studies [35,39] were quasi-experimental because participants were not randomly assigned to a group. Rather, there was only one group in each study, no control, and measures were taken before and after participants took part in mindfulness interventions, and again at follow-up. One study attempted to reduce bias by ensuring that quantitative analysis was carried out by researchers who were independent of the intervention [39]. Three studies were pilots [35,39,28], i.e. aimed to assess the feasibility of mindfulness interventions for specific populations, and Carson et al. [35] declared there were no a priori hypotheses, accordingly.

Attrition rates, follow-ups, and recruitment

A pattern can be seen across all six studies, whereby the longer the follow-up, the higher the attrition rate. For example, a study with a one-month follow-up reported an attrition rate that was then calculated to be 20% [42], whereas at six months, there was an attrition rate of 47% [26]. The study with the lowest attrition rate also had the highest number of initial participants (n=60).

Four studies had follow-ups, and the average length was 3.5 months. Of these, only one could not report reasons for attrition because the follow-up was a paper-based measure sent through the post. The most common reasons stated for participants dropping out were death or illness (n=22), which accounted for 10% of the total participants in all studies. It is fair to assume these numbers could be higher, as further numbers were given but not separated by reason [28], and also given the 9 participants whose reasons for dropping out were unknown [26]. The only study to financially reward participants each time they completed measures [35], was also the only study to have retained all participants post-intervention.

Recruitment methods were divided. All participants were recruited from oncology clinics, either within hospitals or specialist cancer centres, and all were outpatients. Two studies used a mixture of self-selection, whereby posters, flyers and leaflets were used to advertise the study, alongside referrals from oncologists or clinical staff [26,28]. Otherwise, oncology or urology staff were used to identify appropriate patients and in this sense acted

as clinical gatekeepers; although the criteria by which they selected suitable patients is unreported. The two highest attrition rates (47%, 46%) were from studies that had used self-selection to recruit participants [26,28].

ii. Use of mindfulness interventions

MBSR

Two studies reported MBSR interventions [26,42], though there was large variation in their deliveries. One was a group intervention with seven, weekly, 90-minute sessions including many mindfulness components, and home practice (suggested amount not specified) [26]. By comparison, the other did not involve a group or face-to-face contact time, relying on participants to practice at home using a body scan meditation CD for 45 minutes per day. These participants also received weekly telephone calls to encourage them to practice, and had initial body scan meditation training for 90 minutes, delivered by a trainer.

MBCT

One study reported an MBCT intervention [39], which shared many components of the MBSR intervention [26], but lasted for 30 minutes longer each week and was one week longer in duration. The studies differed in their aims however, as the MBSR intervention had looked for the impact of MBSR on mood disturbance and symptoms of stress; whereas MBCT was being piloted to assess its feasibility [39]. The MBCT intervention had been adapted for a cancer population and its elements reflected this, e.g. including the topic of adjustment to progressive illness. A detailed programme structure was outlined, which was not reported in the MBSR studies.

Other

Two simplified interventions were found. One intervention was a Yoga of Awareness Programme (YAP) [35] and one described itself as a brief wellbeing intervention [28]. The YAP intervention included similar stretching, education and mindfulness components to those in the MBSR [26] and MBCT [39] interventions. The brief wellbeing intervention (BWI) [28] only required participants to practice body scan meditation from a CD for 20 minutes per day, and to keep a diary.

iii. Effectiveness

Carlson et al. [26,40] reported that an MBSR intervention for 19 palliative patients led to significant reductions in physiological and psychological symptoms of stress, and a decrease in mood disturbance. These improvements were best predicted by attendance rate and were sustained at six month follow-up, for the low number of palliative patients who completed the follow-up measures (n=10). Multiple regressions revealed no effects of age, cancer stage or cancer duration on any measures. Surprisingly, later stage of cancer predicted lower initial mood disturbance, whereas being female and educated was an initial predictor of higher stress. Higher educational level and high initial mood disturbance predicted the largest improvements on stress symptoms. The study also found the most improvement on anxiety, anger, and depressive subscales, rather than on

those for physiological symptoms of stress such as heart rate or muscle tension. A dose-response effect was found, as the amount of home practice predicted pre-post improvement in mood.

Carson et al. [35] reported positive findings from a pilot study using a Yoga of Awareness Programme, which had a small sample (n=13), no control group and no follow-up. However, despite low statistical power, there were statistically significant increases in ratings of daily invigoration and acceptance, and trends for lower pain and higher relaxation. A dose-response effect was again found, between the amount of practice and improved levels of pain, invigoration, and acceptance. These effects were also sustained the next day. Uniquely, the baseline measures of the sample and those who dropped out prior to starting the intervention were compared, and revealed that dropouts had lower levels of fatigue. Post-intervention focus group findings indicate that women found being in the company of other women with metastatic breast cancer very valuable. Mindfulness groups were declared feasible for this population, with further evidence and more studies needed.

Chambers et al. [39] found significant changes in both psychological and cancer-specific distress, as demonstrated by changes in levels of avoidance, anxiety, and mindfulness skills from baseline to post-intervention, and at three month follow-up. They reported moderate to large effect sizes, with the largest for avoidance. There was no effect found for quality of life or physical functioning. Meditation and moment-to-moment awareness were rated as the most helpful aspects of the intervention, and again participants found it useful to be part of a group of patient peers. Over half of patients were still practicing mindfulness at follow-up, and one third reported having daily awareness. The intervention was declared to have utility and effectiveness for cancer patients.

Ramachandra et al. [28] concluded that a brief wellbeing intervention was feasible and acceptable to patients with cancer. There was significant improvement in quality of life, and improvement in post-intervention anxiety and depression scores, though these were not significant. There was no change in overall functioning. Participants interestingly cited that their motivation to participate had been due to gratitude and altruism, rather than for personal gain. There were gender differences in daily compliance rates, where 73% women recorded daily positive activities compared to 67% of men. This reversed for use of the body scan CD, where 59% women compared to 61% men reported daily use.

Tsang et al. [42] reported that terminal cancer patients had baseline scores on the Short Form Health Survey (SF-36) that were only 37-42% of those of a population without cancer, suggesting that their physical and mental health was well below average at the start of the study. There was no difference in baseline scores between the control and intervention groups however, despite having cancer in different sites. Body scan meditation (BSM) had no effect on physical function, physical role functioning or general health perceptions. BSM did however, have significant effects on scores of vitality, social functioning, mental health, and overall mental component scores. These effects were only significant after one month of practice, and not at one week post-intervention. There was no duration reported for the study, though it was

suggested that effects of BSM could continue to increase up to six months if practice was maintained.

Conclusions

Effectiveness

There is evidence for the effectiveness of mindfulness interventions on psychological outcomes. Studies consistently reported improvements in anxiety and depression rated on standardised measures with high validity and reliability, e.g. HADS [26,28,39]. Although one study reported significant effects on physical measures [26], these were found to be less significant than effects on the psychological aspects of anger and depression. Two further studies found no effect of MBSR or MBCT on physical functioning [39,42], though given the population had advanced cancer this is perhaps unsurprising. However, the perception of physical pain is perhaps shown to have shifted, as participants reported lower levels of pain [35,42]. Although the physical reasons for their pain are unlikely to have changed, the influence of cognitive processes upon subjective levels of pain is well-established in healthcare literature [49], and has also been demonstrated by the success of mindfulness-based interventions at lessening chronic pain [9,16].

Relating to theory

A dose-response relationship was reported in three studies [26,35,42], between the time spent practicing meditation and the strength of its impact on many variables, such as mood, mental health, pain, and acceptance. This has implications for future interventions, and practice should be encouraged. That the ongoing practice of meditation should continue to foster improvements is in line with Shapiro's theory that mindfulness facilitates and accelerates the process of *reperceiving*, i.e. shifting perspective and becoming able to observe events rather than to become embedded within them [7]. The theory that this shift could be achieved through the mechanisms of intention, attitude, and attention finds support in several of the studies in this review.

A later stage of cancer predicted a lower level of mood disturbance before intervention, despite patients facing the end of life. If they have supposedly overcome existential anxiety, this may have been due to an increased degree of acceptance of their situations. Acceptance is a component of mindfulness found in Acceptance and Commitment Therapy [6], which refers to a willingness to experience unpleasant thoughts and feelings; much like Shapiro's axiom of 'attitude.' Furthermore, ACT posits that avoidance of unpleasant experiences is the opposite of acceptance, and levels of avoidance were shown to decrease following an MBCT intervention [39]. Belonging to a group was very positive for participants, and it could be that interacting with other people in similar conditions helped to increase acceptance, and to foster a common attitude towards their illnesses, thus moving participants towards *reperceiving*.

Methodological issues

Studies were mixed in methodological quality. The generalisability of results may have been compromised by small sample sizes, a lack of control groups, and the influence of extraneous variables on participants, e.g. participation in

other psychotherapeutic interventions [42]. Where participants were self-selected, they may have been motivated and not necessarily representative of a wider population. Contrastingly, the heterogeneity of participant groups in terms of cancer site and stage was beneficial, therefore demonstrating that groups do not necessarily need to be homogenous and tightly controlled in order to be effective. There was a lack of reporting of negative findings, both in the initial papers identified for review and within the papers themselves, which suggests reporting bias is present. Many papers were excluded on the basis of not including, or not distinguishing a palliative sample. This selection bias demonstrates that palliative patients remain under-represented in cancer research [35], and researchers may deliberately exclude them from studies to insure that they do not diminish effect sizes, as they are likely to show less change than participants who can recover [42]. Furthermore, participants were entirely older adults, excluding those who face the end of life at a young age from intervention.

Intervention use

Interventions were variable in their deliveries of MBSR. There was a lack of reporting about MBSR and MBCT facilitators, who are required to practice ongoing mindfulness and have access to supervision; which was only reported in one study [39]. One intervention only required participants to listen to a body scan meditation CD at home, rather than engaging them in the group-based format [42]. No interventions included a full day's meditation, as recommended, but contact time was not necessarily indicative of better results, in line with previous findings [50]. Furthermore, it is not possible to separate the impact that group membership and social interaction might have had from the content of the mindfulness intervention and meditative practice itself. Results from larger, more inclusive MBSR or MBCT interventions could not differentiate between mindfulness components to establish which are the most effective. However, the more simplistic interventions which reported significant results [28,42] could be helpful in this endeavour. Both utilised body scan meditation and found improvements on several factors already discussed. In order to ascertain whether body scan meditation is sufficient to deliver maximum effectiveness, or whether including other components is necessary, further research is needed. Similarly, to continue exploring which active components have the most use and effectiveness for a given population, calls for dismantling studies are supported [7].

Overall, there was a high rate of attrition, which worsened as study length increased, and this was lowest in the study with the shortest follow-up time and fewest measures. This may imply that there is an optimum length of time between one and two months for mindfulness interventions with a palliative population; particularly as results showed mindfulness to be very effective when practiced outside of formal sessions, away from the demands of contact time. Follow-up times varied from one to six months, and although the most common reason for attrition was death or illness, it is likely that due to the physical demands of palliative illness, participants are also combatting cancer-related fatigue [26,35], which may contribute to attrition. Therefore, interventions need to be further adapted to suit the palliative population by placing fewer demands on their time. Furthermore, studies which utilised technology to deliver mindfulness interventions, and did not require contact

time, found reduced pain ratings and increased quality of life, vitality, mental health and social functioning [28,42]. Adapted interventions could also prove more time-efficient for both patients and healthcare staff, and may be more cost-effective. These could include increased use of technology [39], shorter measures and less time face-to-face, depending on participant preference. Continued research into the best adaptations of interventions for this population is therefore recommended, in order to maximise their access to appropriate psychological support, in line with NICE guidelines [34].

Limitations

This review is limited in that it has assessed the quality of studies based upon their write-ups, which may or may not be of high quality. Furthermore, it only included English language papers, and used only one rater to determine the quality of studies selected.

Summary

The results of mindfulness-based interventions in palliative cancer care are promising, although cannot be taken to show causality or generalisability due to methodological limitations. Congruent with the findings of previous reviews [2,36], there are no conclusive findings for the effectiveness of mindfulness on quality of life, despite evidence for its impact on psychological and affective domains. The palliative cancer population remains under-represented and under-researched, but overall mindfulness interventions could be both useful and effective, provided future interventions are adapted to reflect the unique needs of this group.

References

- [1] Kabat-zinn, J. Mindfulness-Based Interventions in Context: Past, Present, and Future. *Clin Psychol*. 2003; **10**: 144-156. doi: 10.1093/clipsy.bpg016
- [2] Shennan C, Payne S, Fenlon D. What is the evidence for the use of mindfulness-based interventions in cancer care? A review. *Psychooncology*. 2011; **20**(7): 681–97.
- [3] Segal, ZV, Williams, JNG & Teasdale, JD. *Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse*. New York: Guilford Press; 2002.
- [4] Kabat-Zinn, J. *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*. Delta Trade Paperbacks: New York; 1990.
- [5] Linehan, MM. *Cognitive Behavioural Treatment of Borderline Personality Disorder*. New York: Guilford Press; 1993.
- [6] Hayes, SC, Strosahl, KD & Wilson, KG. *Acceptance and Commitment Therapy: An Experiential Approach to Behavior Change*. New York: Guilford Press; 1999.
- [7] Shapiro SL, Carlson, LE, Astin, JA, Freedman B. Mechanisms of mindfulness. *J Clin Psychol*. 2006; **62**(3): 373-386.
- [8] Kabat-Zinn, J, Massion, AO, Kristeller, J, Peterson, LG, Fletcher, KE, Pbert, L, et al. Effectiveness of a meditation-based stress reduction programme in the treatment of anxiety disorders. *Am J Psychiatry*. 1992; **149**: 943-963.
- [9] Kabat-Zinn, J, Lipworth, L, Burney, R & Sellers, W. Four-year follow-up of a meditation-based program for the self-regulation of chronic pain: treatment outcomes and compliance. *Clin J Pain*. 1986; **2**: 159-173.
- [10] Jin, P. Efficacy of tai chi, brisk walking, meditation and reading in reducing mental and emotional stress. *J Psychosom Res*. 1992; **36**: 361-70.
- [11] Carlson, LE, Speca, M, Faris, P, Patel, KD. One year pre-post intervention follow-up of psychological, immune, endocrine and blood pressure outcomes of mindfulness-based stress reduction (MBSR) in breast and prostate cancer outpatients. *Brain Behav Immun*. 2007; **21**: 1038-1049.
- [12] Hölzel, BK, Lazar, SW, Gard, T, Schuman-Olivier, Z, Vago, DR & Ott, U. How Does Mindfulness Meditation Work? Proposing Mechanisms of Action From a Conceptual and Neural Perspective. *Perspect Psychol Sci*. 2011; **6**(6): 537-559.
- [13] Beauregard, M, Levesque, J & Bourgouin, P. Neural Correlates of Conscious Self-Regulation of Emotion. *J Neurosci*. 2001; **21**: 1-6.

- [14] Beck, AT. *Cognitive therapy and the emotional disorders*. New York: International Universities Press; 1976.
- [15] Proudfoot, J, Ryden, C, Shapiro, DA, Goldberg, G, Marks, A & Gray, J. Clinical efficacy of computerised cognitive-behavioural therapy for anxiety and depression in primary care: randomised controlled trial. *Brit J Psychiat*. 2004; **185**: 46-54.
- [16] Hoffman, BM, Papas, RK, Chatoff, DK, Kerns, RD. Meta-analysis of psychological interventions for chronic low back pain. *Health Psychol*. 2007; **26**(1): 1-9.
- [17] Arch, JA, Ayers, CR, Baker, A, Almklov, E, Dean, DJ & Craske, MG. Randomized clinical trial of adapted mindfulness-based stress reduction versus group cognitive behavioral therapy for heterogeneous anxiety disorders. *Behav Res Ther*. 2013; **51**: 185-196.
- [18] Beck, AT, Rush, A, J, Shaw, BF & Emery, G. *Cognitive Therapy of Depression*. New York: Guilford Press; 1979.
- [19] Kaviani, H, Javaheri, F & Hatami, N. Mindfulness-based Cognitive Therapy (MBCT) Reduces Depression and Anxiety Induced by Real Stressful Setting in Non-clinical Population. *Rev Int Psicol Ter Psicol*. 2011; **11**(2): 285-296.
- [20] Williams, JMG, Russell, I & Russell, D. Mindfulness-Based Cognitive Therapy. Further Issues in Current Evidence and Future Research. *J Consult Clin Psychol*. 2008; **76**(3): 524-529.
- [21] Coelho, HF, Canter, P & Ernst, E. Mindfulness-Based Cognitive Therapy. Evaluating Current Evidence and Informing Future Research. *PSYCON*. 2013; **1**: 97-107.
- [22] Baer, R. Mindfulness Training as a Clinical Intervention: A Conceptual and Empirical Review. *Clin Psychol-Sci Pr*. 2006; **10**(2): 125-143.
- [23] Weissbecker, I, Salmon, P, Studts, J, Floyd, A, Dedert, E & Sephton, S. Mindfulness-Based Stress Reduction and sense of coherence among women with fibromyalgia. *J Clin Psychol Meds*. 2002; **9**(4), 297-307.
- [24] Robinson, F, Mathews, H & Witek-Janusek, L. Psychoendocrine-immune response to Mindfulness-Based Stress Reduction in individuals infected with the human immunodeficiency virus: a quasiexperimental study. *J Altern Complem Med*. 2003; **9**(5): 683-694.
- [25] Miller, JJ, Fletcher, K & Kabat-Zinn, J. Three-year follow-up and clinical implications of a mindfulness-based stress reduction intervention in the treatment of anxiety disorders. *Gen Hosp Psychiat*. 1995; **17**(3): 192-200.

- [26] Carlson LE, Ursuliak Z, Goodey E, Angen M, Specia M. The effects of a mindfulness meditation-based stress reduction program on mood and symptoms of stress in cancer outpatients: 6-month follow-up. *Support Care Cancer*. 2001; **9**(2): 112-123.
- [27] Pasacreta, V. Depressive phenomena, physical symptom distress and functional status among women with breast cancer. *Nurs Res*. 1997; **46**: 347-353.
- [28] Ramachandra P, Booth S, Pieters T, Vrotsou K, Huppert FA. A brief self-administered psychological intervention to improve well-being in patients with cancer: Results from a feasibility study. *Psychooncology*. 2009; **18**(12): 1323-1326.
- [29] Australian Cancer Network Management of Metastatic Prostate Cancer Working Party. *Clinical practice guidelines for the management of locally advanced and metastatic prostate cancer*. [Document on the internet]. Sydney: Cancer Council Australia and Australian Cancer Network; 2010 [cited 2014 Aug 07]. Available from: https://www.andrologyaustralia.org/wp-content/uploads/FINAL_Advanced_Prostate_Cancer_Guidelines.pdf
- [30] Bill-Axelsson, A, Garmo, H, Lambe, M, Bratt, O, Adolfsson, J, Nyberg, U, et al. Suicide risk in men with prostate-specific antigen-detected early prostate cancer: a nationwide population-based cohort study from PCBaSe Sweden. *Eur Urol*. 2010; **57**: 390-395.
- [31] Lengacher, CA, Kip, KE, Barta, M, Post-White, J, Jacobsen, PB, Groer, M, et al. A Pilot Study Evaluating the Effect of Mindfulness-Based Stress Reduction on Psychological Status, Physical Status, Salivary Cortisol, and Interleukin-6 Among Advanced-Stage Cancer Patients and Their Caregivers. *J Holist Nurs*. 2012; **30**(3): 170-185.
- [32] Leydon GM, Eyles, G & Lewith, G. A mixed methods feasibility study of mindfulness meditation for fatigue in women with metastatic breast cancer. *EuJIM*. 2012; **4**: 429-435.
- [33] Mystakidou, K, Parpa, E, Tsilika, E, Pathiaki, M, Gennatas, K, Smyrniotis, et al. The relationship of subjective sleep quality, pain, and quality of life in advanced cancer patients. *Sleep*. 2007; **30**: 737-742.
- [34] National Institute for Health and Clinical Excellence. Improving Supportive and Palliative Care for Adults with Cancer. The manual. [Document on the internet]. London: NICE; 2004 [cited 2014 Aug 07]. Available from: <http://www.nice.org.uk/guidance/csgsp/resources/supportive-and-palliative-care-the-manual>
- [35] Carson JW, Carson KM, Porter LS, Keefe FJ, Shaw H, Miller JM. Yoga for Women with Metastatic Breast Cancer: Results from a Pilot Study. *J Pain Symptom Manage*. 2007; **33**(3): 331-341.

- [36] Smith, JR, Hoffman, C & Pilkington, K. Mindfulness-Based Stress Reduction as supportive therapy in cancer care: systematic review. *J Adv Nurs*. 2005; **52**(3): 315-327.
- [37] Dickersin, K, Scherer, R, Lefebvre, C. *Identifying relevant studies for systematic reviews*. In: Chalmers, I & Altman, DG, editors. *Systematic Reviews*. London: BMJ Publishing Group; 1995.
- [38] National cancer intelligence network. *Survival in Teenagers and Young Adults with Cancer in the UK*. [Document on the internet]. Manchester: North West Cancer Intelligence Service; 2012 [cited 2014 Aug 07]. Available from: file:///Users/lucindabrabbins/Downloads/UK_report_forpublication_august2012_v2.pdf
- [39] Chambers SK, Foley E, Galt E, Ferguson M, Clutton S. Mindfulness groups for men with advanced prostate cancer: A pilot study to assess feasibility and effectiveness and the role of peer support. *Support Care Cancer*. 2012; **20**(6): 1183-1192.
- [40] Specia, M, Carlson, L, Goodey, E, Angen, M. A Randomized, Wait-List Controlled Clinical Trial: The Effect of a Mindfulness Meditation-Based Stress Reduction Programme on Mood and Symptoms of Stress in Cancer Patients. *Psychosom Med*. 2000; **62**: 613-622.
- [41] Chambers, SK, Smith, DP, Berry, M, Lepore, SJ, Foley, E, Clutton, S, et al. A randomised controlled trial of a mindfulness intervention for men with advanced prostate cancer. [Study protocol]. *BMC Cancer*. 2013; **13**: 89.
- [42] Tsang SC, Mok ES, Lam SC, Lee JK. The benefit of mindfulness-based stress reduction to patients with terminal cancer. *J Clin Nurs*. 2012; **21**(17-18): 2690-2696.
- [43] Myers, M. Qualitative Research and the Generalizability Question: Standing Firm with Proteus. *Qual Rep*. [Serial Online]. 2000 [cited 2014 Aug 07]; **4**. Available from: <http://www.nova.edu/ssss/QR/QR4-3/myers.html>
- [44] Evans, D. Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *J Clin Nurs*. 2003; **12**: 77-84.
- [45] Cunningham, AJ, Phillips, C, Lockwood, GA, Hedley, DW, Edmonds, CVI. Association of involvement in psychological self-regulation with longer survival in patients with metastatic cancer: An exploratory study. *Adv Mind Body Fal*. 2000; **16**(4): 276-286.
- [46] Song, F, Parekh, S, Hooper, L, Loke, YK, Ryder, J, Sutton, AJ, et al. Dissemination and publication of research findings: an updated review of related biases. *Health Technol Assess*. 2010; **14**(8): 4-11.
- [47] Higgins, JPT, Green, S. *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0. [Updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.

- [48] National Collaborating Centre for Methods and Tools. *Quality Assessment Tool for Quantitative Studies*. Hamilton: McMaster University; 2010.
- [49] Skevington, SM. *Psychology of Pain*. Oxford: John Wiley & Sons; 1995.
- [50] Carmody, J, Baer, RA. How long does a mindfulness-based stress reduction program need to be? A review of class contact hours and effect sizes for psychological distress. *J Clin Psychol*. 2009; **65**(6): 627-638.

Appendices

Appendix A. Results Tables

Table 8. Study characteristics and key findings

First author, year, location & reference number	Overall sample size (N) and number of terminal patients (n)	Participant demographics	Intervention	Main findings
Carlson et al.* (2001) [26, 40] Canada	N=89 n=19	m=17, f=72. Mixed sites & stages Mean age=52	MBSR	<p>Significant reduction in mood and stress scores pre to post, and post to follow-up. Less mood disturbance ($p<0.001$) and reduction in stress symptoms ($p<0.001$) compared to controls. Effects were sustained over time (6 months).</p> <p>Time spent practicing meditation predicted change in rated mood disturbance ($p<0.03$), but level of attendance did not. Average daily practice was 32 minutes. Number of sessions attended predicted change in stress symptoms ($p<0.05$).</p> <p>Cancer stage predictive of lower mood disturbance at baseline; later stage cancer predicted lower total mood disturbance ($p<0.02$). Dropouts had significantly higher levels of anxiety, fatigue and total mood disturbance ($p<0.05$).</p>

Carson et al. (2007) [35] USA	N=13 n=13	f=13 Metastatic breast Mean age=59	YAP	<p>Significant improvements in daily invigoration ($p<0.01$) and acceptance ($p<0.02$).</p> <p>Increased practice time predicted lower pain the next day ($p<0.01$), and also the day after ($p=0.03$).</p> <p>No significant differences in the demographics of completers and drop-outs, but completers had higher levels of fatigue ($M=46.92$) compared to drop-outs ($M=26.15$), and lower levels of relaxation ($M=45.21$) compared to drop-outs ($M=63.16$), at baseline.</p>
Chambers et al. (2012) [39] Australia	N=19 n=19	m=19 Prostate Mean age=67	MBCT	<p>Changes in psychological and cancer-specific distress demonstrated by significant differences between baseline and follow-up scores for anxiety ($p=0.0027$) and avoidance ($p=0.032$).</p> <p>There was no significant effect on quality of life was found. There was increased mindfulness over time, and a trend for increased observation and decreased reactivity to inner experience.</p>
Ramachandra et al. (2009) [28] UK	N=46 n=46	m=24, f=22 Metastatic breast Metastatic prostate Mean age=72.4	BWI	<p>Rated quality of life significantly improved ($p=0.046$), which was also reflected in qualitative interviews.</p> <p>Anxiety and depression scores improved, but the change was not significant ($p=0.088$). There was no change in overall functioning.</p> <p>Compliance rates were reported: 71% reported daily in diaries, and 60% did the meditation at least once per day.</p> <p><i>Qualitative findings</i></p> <p>Participants reported the diary helped them to notice positive events, but</p>

				that both recording in the diary and the CD was repetitive. The CD was reportedly too basic; participants wanted increased length and complexity.
Tsang et al. (2012) [42] Hong Kong	N=60 n=60	m=26, f=22 Mixed sites Mean age =71.4	MBSR	<p><i>Physical effects</i></p> <p>Practicing BSM significantly reduced pain after one week ($p=0.00$), and lower pain was related to increased overall physical health scores, compared to control. Effect on pain was greater after one month of continuous practice ($p=0.000$).</p> <p><i>Mental effects</i></p> <p>Practicing body scan meditation (BSM) significantly improved vitality, social function, mental health and overall mental component score ($p=0.000$). Effects only reached statistical significance after one month of continuous practice.</p>

*Denotes 6-month follow-up of an RCT [ref] also included in the final review, but not included in the tabulated data to avoid replication.

Abbreviations. MBSR, Mindfulness Based Stress Reduction; YAP, Yoga of Awareness Programme; MBCT, Mindfulness-Based Cognitive Therapy; BWI, Brief Wellbeing Intervention.

Table 9. Methodological properties

Study	Overall sample size, sampling technique & representativeness rating (R1-R3)	n at post and follow-up	Follow-up length	Attrition rate & reasons	Study design	Standardised measures & frequencies	Randomisation (R), Control (C), Blinding (B), Partial blinding (PB)	Quality rating
Carlson et al. (2001) [26,40]	N=89 Self-selected and purposive R3	n=19 Post, n=19 Follow-up, n=10	6 months	Follow-up = 47% Reasons stated as unknown	RCT- waiting list control	<i>i.</i> POMS SOSI B, P, F <i>ii.</i> Record of amount of home practice (mins) B, P	R C - -	M
Carson et al. (2007) [35]	N=13 Purposive R2	n=13 Post, n=13	-	-	Pilot study Single group, pretest-posttest design, with repeated measures	<i>i.</i> Diary ratings using visual analogue scales B, D, P <i>ii.</i> Focus group & bespoke questionnaire (not specified) P	- - -	M

Chambers et al. (2012) [39]	N=19 Self-selected and purposive R3	n=19 Follow-up, n=12	3 months	Post = 37% Death (n=2), withdrawal (n=1), not reported (n=4)	Pilot study Single group, pretest-posttest design, with repeated measures	HADS IES-R MAX-PC EPIC FACT-P FFMQ B, P, F Qualitative questions (method not stated) Semi-structured interviews P	- - - PB	W
Ramachandra et al. (2009) [28]	N=46 Purposive R2	n=46 Post, n=27 Follow-up, n=25	3 months & 4.5 months	Post = 41% Follow-up = 46% Death (n=7), illness, other commitments and disengagement (n=14)	Feasibility study RCT –waiting list control	LOT-R TIPI B SOFAS WHO QOL-BREF Semi-structured interview B, F Wellbeing diary D	R C - -	W

Tsang et al. (2012) [42]	N=60 Purposive R2	n=60 post, n=48	1 month	Post = 20% Death, admission to hospital (n=12)	RCT – no treatment control	SF-36 B, P, F	R C - -	M
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Note: 1. Overall sample size & representativeness rating: N=Overall population, n=population with terminal cancer. R1=very likely (participants randomly selected from a list of individuals in the target population), R2=somewhat likely (referred from a source in a systematic manner), R3=not likely (self-referred), 4=can't tell. **2. Standardised outcome measures and frequencies:** B = baseline, P = post, F = follow-up, D = daily. **3. Quality Rating:** S = Strong, M = Moderate, W =Weak.

Abbreviations: POMS, Profile of Mood states; SOSI, Symptoms of Stress Inventory; HADS, Hospital Anxiety and Depression Scale; IES-R, The Revised Impact of Events Scale; MAX-PC, Memorial Anxiety Scale for Prostate Cancer; EPIC, The Expanded UCLA Prostate Cancer Index; FACT-P, The Functional Assessment of Cancer Therapy -Prostate; FFMQ, The Five Facet Mindfulness Questionnaire; WHO QOL-BREF, WHO Quality of Life Scale, SOFAS, Social and Occupational Functioning Assessment Scale; LOT-R, Life Orientation Test; TIPI, Ten-Item Personality Inventory; SF-36, Short Form (36) Health Survey.

Table 10. Interventions

Study	Intervention characteristics	Duration and intervention type	Daily recommended practice (minutes) & any aids	Follow-up length & method	Facilitators	Uncontrolled variables
Carlson et al. (2001) [26,40]	<p>MBSR</p> <p>Weekly, 90 minute sessions</p> <p>Cancer clinic</p> <ul style="list-style-type: none"> ○ Weekly psychoeducation/guided discussion about theory ○ Body scan ○ Breathing ○ Guided meditation ○ Yoga poses ○ Group discussion of any intervention challenges ○ Home-based practice 	<p>7 weeks</p> <p>G, I</p>	<p>Not stated</p> <p>Booklet covering weekly topics and audiotape of relaxation and guided meditation</p>	<p>6 months</p> <p>M</p>	No information on facilitation/trainers	Extra practice and information was facilitated (e.g. a bibliography was provided), but not controlled for

Carson et al. (2007) [35]	<p>Yoga of Awareness Programme</p> <p>Weekly, 120 minute sessions</p> <p>Breast oncology unit</p> <ul style="list-style-type: none"> ○ Gentle yoga postures ○ Breathing exercises ○ Meditation ○ Guided discussion about theory ○ Group discussion of any intervention challenges ○ Home-based practice 	<p>8 weeks</p> <p>G, I</p>	<p>10 mins per day</p> <p>CD and illustrated handbook</p> <p>Applications to daily living were assigned each week, e.g. acceptance during intervals of pain</p>	<p>-</p>	<p>Each group jointly led by same yoga teacher & health psychologist</p> <p>Manual to provide facilitators with session guidelines</p> <p>Sessions recorded and reviewed by treatment team</p>	<p>Some participants had practiced meditation before</p>
Chambers et al. (2012) [39]	<p>MBCT</p> <p>Weekly, 120 minute sessions</p> <p>Urban and regional cancer centres</p> <ul style="list-style-type: none"> ○ Psychoeducation ○ Body scan ○ Stretching and walking ○ Breathing ○ Meditation <p>Group process</p> <p>Semi-structured interview at 8</p>	<p>8 weeks</p> <p>G, I</p>	<p>35 mins</p> <p>Handbook covering weekly topics and meditation CD</p>	<p>3 months</p> <p>Ms</p>	<p>Psychologists, trained in MBCT, who also had supervision</p> <p>Manual to provide facilitators with session guidelines</p>	<p>Optional extra 4-hour meditation session conducted at week 6</p>














	weeks					
Ramachandra et al. (2009) [28]	<p>Brief, self-administered wellbeing intervention</p> <p>Oncology clinic (for briefing and interviews)</p> <ul style="list-style-type: none"> Record 3 positive experiences per day Mindfulness CD (body scan) Planning pleasurable activities 	<p>6 weeks</p> <p>I</p>	<p>20 mins</p> <p>Record diary, CD</p>	<p>3 months & 4.5 months</p> <p>Ms & INT (at home or telephone)</p>	-	
Tsang et al. (2012) [42]	<p>MBSR</p> <p>90 min training in body scan meditation</p> <ul style="list-style-type: none"> Home-based practice Weekly telephone call 	<p>Duration not reported</p> <p>I</p>	<p>45 mins, 5 days per week, using soundtrack CD</p>	<p>1 month</p> <p>M</p>	<p>Trainer with audio soundtrack of body scan</p>	<p>Participants had differing participation in other palliative activities at day centre, e.g. groups or psychotherapy</p>

Note. 1. Duration & Intervention Type: G=group, I=individual therapy. **Follow-up length & Method:** M(s) = Measure(s) re-administered at follow-up, INT = Semi-structured interview.

Appendix B. Database search terms

▼ Search History (6 searches) (close)

View Saved

<input type="checkbox"/>	# ▲	Searches	Results	Search Type	Actions	CONTRACT
<input type="checkbox"/>	1	(mindfulness or meditat* or "mindfulness meditation" or MBCT or MBSR or MBSR-C or "Acceptance and Commitment Therapy").mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	8179	Advanced	 Display  Delete  Save More »	
<input type="checkbox"/>	2	(Therap* or treatment or intervention or psych* or training or practice or practise).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	8203309	Advanced	 Display  Delete More »	
<input type="checkbox"/>	3	(cancer or oncology or neoplasm or tumo#r).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	2359072	Advanced	 Display  Delete More »	
<input type="checkbox"/>	4	(dying or terminal or palliative or "stage 4" or "stage four" or "stage vi" or "grade d" or "end of life" or metasta* or incurable or advanced).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]	1313281	Advanced	 Display  Delete  Save More »	
<input type="checkbox"/>	5	1 and 2 and 3 and 4	159	Advanced	 Display More »	
<input type="checkbox"/>	6	limit 5 to (human and english language and (adult <18 to 64 years> or aged <65+ years>))	33	Advanced	 Display More »	
Remove Selected		Save Selected	Combine selections with: And Or		 RSS	
Save Search History						